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ABSTRACT

The report describes a 1.5-year project to create a comprehensive plan for the development of residential services for persons with developmental disabilities in New Mexico. Findings represent input from advocates, family members, state officials, community representatives, legislators, and local service administrators. Part One of the report describes the context and guiding concepts for the plan, touching on issues of service system design, implementation, and overall goals. An overview of the target population is also presented. Information collected on the incidence and prevalence of developmental disabilities in the state is reviewed, service demands projected, and the current service system described in comparison to other states. Part Two of the report presents the phased objectives that comprise the recommendations for system development and expansion over the next five years. Objectives cover all aspects of implementation, including planning, needs assessment, quality assurance and monitoring, system organization, resource development, management and information, finance, and interagency cooperation. The report includes references, 41 figures, and five appendices (sample survey forms and interview guide, descriptions of levels of functioning and of client services, and information on the Inventory for Client and Agency Planning. (JW)

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Plan for the Development and Improvement of Residential Services for Persons With Developmental Disabilities

HSRI

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Plan for the Development and Improvement of Residential Services for Persons With Developmental Disabilities

Prepared for:

The New Mexico Developmental Disabilities
Planning Council

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PART ONE

I. INTRODUCTION

The following document represents the results of a year and a half long project to develop a comprehensive plan for the development of residential services for persons with developmental disabilities in New Mexico. It reflects a variety of activities aimed at assessing current system characteristics, determining the level of need for residential services, exploring funding alternatives, and surveying community and provider perceptions of necessary service directions. The findings represent a wide spectrum of input from advocates, family members, state officials, community representatives, legislators, and local service administrators. They also have been developed with a recognition of national programmatic and funding trends.

A. Background of the Project

The Human Services Research Institute has been under contract to the New Mexico Developmental Disabilities Planning Council since the Fall of 1984 and has carried out a variety of tasks that have yielded that information necesarry for the preparation of the ensuing plan.

1. Public forums were conducted in each planning district in the state. The purpose of these meetings was to provide concerned persons in New Mexico with an opportunity to express their view of the current service system and what must be done to improve it.

2. To collect information on the types and nature of services offered around the state, the persons receiving these services and the demand for services, project staff conducted a survey of providers from March 1985 to May 1985 (see Appendix for a copy of the survey).

3. Interviews were conducted with numerous individuals around the state in order to gain a better

understanding of service delivery issues, service expectations, and the constraints and facilitating factors that are likely to influence the system of services for developmentally disabled persons. A wide variety of individuals were contacted including state officials in the Departments of Human Services, Health and Environment, Education and Corrections; local service providers; legislators and legislative staff; academics and advocates; family members and representatives of consumer and provider organizations (see Appendix for a copy of the interview guide).

4. To fill gaps in knowledge and to enhance our understanding of the system, project staff reviewed information available from a variety of other sources including program evaluations, statutes and regulations, policy memos and so forth.

5. In order to develop estimates of the incidence and prevalence of developmental disabilities in New Mexico, several national data bases were consulted and analyzed.

6. Representatives were selected from each of the seven planning districts to review preliminary prevalence and service utilization data.

7. Profiles were prepared for each planning district which included information on local needs, client characteristics, and patterns of service. Responses to the profiles assisted project staff in the preparation of the final plan.

8. A report was prepared on the incidence and prevalence of developmental disabilities as well as the potential demand for services and was submitted to the Council.

The final task in the project was to review all of the information collected and analyzed in the above activities and to synthesize it into a comprehensive plan for residential services development.

B. Organization of the Plan

The ensuing plan is organized into two parts. Part One provides the context and basis for the plan and includes several sections. The first portion of Part One describes the national service and political context, the concepts that underlie the plan including service system principles (e.g., integration, equity, etc.) and implementation considerations (e.g., staging, comprehensiveness, etc.). The second section of Part One reviews the information collected on the incidence and prevalence of developmental disabilities in the state as well as projections of service demand. The third section describes the current service system in the state and compares New Mexico to other states in the country.

Part Two of the plan presents the phased objectives that comprise HSRI's recommendations for system development and expansion over the next five years. Objectives have been developed to govern all aspects of implementation including planning, quality assurance and monitoring, system organization, resource development, management and information, needs assessment, and financing.

II. GUIDING CONCEPTS

The plan for the development of residential services in the State of New Mexico as outlined in Part Two of this report is governed by a number of assumptions about programmatic values, overarching purposes, and implementation strategies. This section provides an introduction to these assumptions and points out the way in which they influence specific aspects of the plan.

A. Service System Design

Residential services for persons with developmental disabilities have been in a period of substantial change for nearaly two decades. Changes in the service system have been shaped by the concepts of normalization and mainstreaming, and by a number of other trends and events such as:

- a growing body of research on the development of mentally retarded persons that shows that such individuals have the ability to grow and to learn -- this research became translated into the "developmental model;"
- the ongoing improvement of instructional techniques that promote learning and the ability to carry out tasks of daily living;
- mounting evidence that for all persons with developmental disabilities long-term institutionalization results in the loss of learning and skills;
- growing evidence of the positive effects of community-based services on learning and the acquisition of daily living skills;
- the use of the courts -- especially the federal courts -- to bring about reforms in institutional care and ultimately to secure services in the community within "least restrictive settings;"
- the passage of major federal legislation such as the Education for All Handicapped Children Act (PL 94-142), Developmental Disabilities Act (PL 94-103),

Rehabilitation Act of 1973 (PL 93-112) and Comprehensive Services and Disabilities Amendments of 1979 (PL95-602);

- the initiation of federal programs such as Medicaid and Supplemental Security Income (SSI) which made it possible for states to move persons with developmental disabilities into the community where the cost of shelter and care could be shared with the federal government.

As a result of all of these forces, the field of developmental disabilities has articulated a program philosophy that is perhaps more coherent than that of any other field of human services. Further, given the energetic efforts of many, the underlying philosophy of the field is continually being reinspected and updated so that it is also one of the most dynamic service theories. Such self inspection takes place on a number of fronts and results in heated debates and discussions. However, there is an emerging consensus regarding the following principles:

- Community Integration: Moving individuals out of isolated custodial facilities was only one step toward the development of more normal lives for persons with developmental disabilities. It has become clear more recently that a mere shift in address is not enough to ensure that a person with a developmental disability is truly integrated into his or her community. Program planners have to be alert to the possibilities of segregation in the community resulting from overly large facilities, segregated activities, segregated work activities, and lack of involvement in normal community routines. For instance, taking 30 disabled individuals to a local bowling alley in three vans labeled with the agency's logo is not likely to facilitate the integration of those individuals but will reinforce their separateness. The acceptance of this principle leads to a closer examination of the design principles noted below as well as the development of program standards that encourage and reward integrative services.

- Size: In keeping with the principle of community integration, the issue of size has also become an important design consideration. The smaller the residential arrangement, the easier it is to emulate a homelike environment and the more likely that the clients that live in the home will become integrated into the community. An eight or ten bed group home on a residential block is much more likely to be regarded as "special" or separate than a specialized foster home or a community living arrangement of two or three. To ensure that this principle is woven into the plan of residential services, HSRI recommends that no new living arrangement be developed with more than six beds.

- Age-Appropriateness: This principle basically means that persons with developmental disabilities should be afforded experiences and environments commensurate with their age. Age appropriateness is another design concern related to integration since the treatment of individuals in an age appropriate fashion enhances their acceptability and integration. In terms of the ensuing plan, the principle of age appropriateness strongly supports the notion that children with developmental disabilities, like all other children, require the nurturing surroundings of a home. Therefore, HSRI recommends that the priorities for serving children should be: 1) natural family with necessary supports; 2) specialized foster family; 3) small (under 6 beds) community living arrangement. The acceptance of this principle also requires an immediate re-evaluation of the placements of children at Los Lunas.

- Equity: This principle reflects the importantce of an equitable allocation of resources among persons with developmental disabilities in the state. Acceptance of this principle requires a close examination of the current distribution of resources among the seven planning regions, scrutiny of the needs of Native Americans and other minority communities in the state as well as an assessment of impact of the disproportionate allocation of resources to institutional as compared to community programs.

B. Implementation Considerations

New Mexico is in an enviable position as it begins the process of implementing a five years plan for the development and expansion of residential services -- it can take advantage of the mistakes and missteps of other states. Such problems can be summed up in one general failing -- the lack of a systematic and multi-faceted plan of implementation. Too often, major reforms have gone forward without a full understanding of all of the program and financing components that are necessary to ensure a smooth transition from one system to another. Some of the key elements that have been overlooked have been those related to the "infrastructure" of the system including quality assurance mechanisms, case management, back-up crisis management, and technical assistance.

The plan prepared by the Human Services Research Institute recognizes the need for a comprehensive approach to implementation and lays out all of the major steps that must be undertaken and the timing of each activity. To display activities related to various areas of the service system, the plan has been divided into eight implementation areas:

- Planning: those activities associated with endorsement and dissemination of the plan as well as subsequent refinements and "mid course corrections;"
- Needs Assessment: those tasks necessary to identify priority target groups and to determine their specific service needs;
- Management and Organization: those mechanisms that must be put in place to provide ongoing information regarding those receiving services and those waiting for services and well as to govern entry into and exit from the system;
- System Organization: those structure changes that must be made in the organizations that direct the service system in order to ensure expeditious implementation;
- Resource Development: those steps required to stimulate the development of appropriate services and to support and stabilize services over time;
- Quality Assurance: those mechanisms necessary to monitor the quality of services and to ensure the well-being of the clients of such services;

- Financing: those strategies and mechanisms needed to attract and retain necessary funding as well as to ensure the efficient and equitable distribution of resources;

- Interagency Coordination: those agreements and covenants between and among agencies that will ensure the provision of generic services to persons receiving residential services.

C. Overarching Goals

The final assumptions have to do with the overarching goals that should govern the five year plan. These goals are based on the original charge from the Developmental Disabilities Council, our understanding of the state's Developmental Disabilities Act, our interviews with key participants in the system, and the principles articulated above:

1. The community system for persons with developmental disabilities in New Mexico should be strengthened and expanded;

2. Reliance on large residential facilities should be decreased and the development of small (under six beds) residences should be the aim for the next five years;

3. A strong system of supports for natural families with members with developmental disabilities should be developed.

III. OVERVIEW OF THE TARGET POPULATION

A. Prevalence of Developmental Disabilities in New Mexico

The size of the developmentally disabled population can be represented in terms of the incidence of prevalence. **Incidence** refers to the number of new cases that are manifest during a specified period of time. Incidence rates represent the number of new cases occuring during a specified period of time relative to the number of persons at risk during the same period of time.

Prevalence refers to the number of cases (whether old or new) that are present in a population for a designated time interval or point in time. Prevalence rates represent the total number of cases present in the population relative to the total population.

Incidence and prevalence are interrelated. Prevalence rates vary as a function of the incidence and duration of cases. Theoretically, one could estimate the prevalence of disorders (cases) indirectly from estimates of case incidence and duration. However, reliable information is scant on the expected duration or life expectancy of persons with mental retardation and related developmental disabilities, leaving prevalence rates as the measures of choice.

Few if any states can afford to mount epidemiologic surveys or registries comprehensive enough and of sufficient size to calculate valid and reliable estimates of the incidence and prevalence of most developmental disabilities. To obtain these data New Mexico, like other states, has had to fund studies designed to make use of the results of existing epidemiological data.

HSRI made use of the results of several of these studies, and other data sources as well, to complement and verify these figures. Specifically, to estimate the prevalence of developmental disabilities in New Mexico, HSRI used:

(1) national and state estimates of the prevalence of the developmentally disabled population with no mental retardation for persons ages 6-64 and of the entire developmentally disabled population above age 64, derived by Gollay and Associates, Inc. based primarily on the 1976 Survey of Income and Education (Gollay, 1980 and 1981);

(2) area wide estimates derived primarily from studies compiled by Kiely and Lubin (1983), Abramowicz and Richardson (1975), and Kiely, Lubin and Kiely (1984);

(3) estimates based on epidemiologic data on the incidence and mortality of selected medical conditions that lead to developmental disabilities;

(4) state estimates of the size of the mentally retarded population in New Mexico based on the records of adults receiving Supplemental Security Income payments and Social Security Disability Insurance benefits by reason of mental retardation; and

(5) counts of the number of infants and preschoolers (ages 0-5) on high risk infant registries in those states having mandates to serve disabled children from birth.

As described in HSRI's full technical report on incidence and prevalence, the estimates distilled from these sources are all of limited validity, reliability and scope. However, by analyzing these estimates in combination, it is possible to arrive at a more complete picture of the developmentally disabled population in New Mexico than would otherwise be possible, and to validate concurrently these independent estimates (i.e., to assess the probable validity and reliability of independent estimates according to their degree of consistency).

The following figures display project findings pertaining to the estimated prevalence of developmental disabilities in New Mexico. Figures 1-3 show the number of persons with developmental disabilities living in the state for the years 1985, 1990 and 1995 respectively. The information is presented by overall primary classification (i.e., mental retardation or developmental disabilities and normal intelligence), various age groupings, and by planning district. It should be noted that prevalence estimates regarding primary disability classifications are not provided for children aged 0-5 years. For this age group, information that distinguishes between those with mental retardation and those with other developmental disabilities is scant. Moreover, many believe that for children this young it is difficult and undesirable to apply a label such as "mental retardation." Often the term "developmental delay" is used instead. Thus, given no pressing reason or sound basis for dividing this age cohort by intelligence, no such division is made.

Viewed in other ways Figures 4-6 display this same information through a series of bar graphs and pie charts. Figure 4 depicts the estimated growth in numbers of persons with developmental disabilities over the next ten years by planning district. As shown, the developmental disabilities population is expected to grow over the next several years at an age adjusted rate that averages about 10% every five years. Such growth is in line with overall expectations regarding growth of the full state population. Additionally, Figure 4 reveals that the most people with developmental disabilities reside in planning district 3,

FIGURE 1:

ESTIMATED NUMBER OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, BY AGE IN NEW MEXICO: 1985

AGE GROUP	STATE DEV DISABILITIES			DISTRICT 1 DEV DISABILITIES			DISTRICT 2 DEV DISABILITIES			DISTRICT 3 DEV DISABILITIES			DISTRICT 4 DEV DISABILITIES			DISTRICT 5 DEV DISABILITIES			DISTRICT 6 DEV DISABILITIES			DISTRICT 7 DEV DISABILITIES		
	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER
INFANTS/PRESCHOOL																								
0-2 YEARS	449			66			57			160			26			16			84			40		
3-5 YEARS	799			115			103			285			47			29			149			71		
0-5 YEARS TOTAL	1,248			181			160			445			73			45			233			111		
SCHOOL AGE																								
6-17 YEARS	4,133	2,451	1,682	540	320	220	571	339	232	1,497	888	609	236	140	96	159	94	65	727	431	296	403	239	164
18-21 YEARS	1,011	751	260	120	89	31	133	99	34	388	288	100	62	46	16	35	26	9	156	116	40	117	87	30
6-21 YEARS TOTAL	5,144	3,202	1,942	660	409	251	704	438	266	1,885	1,176	709	298	186	112	194	120	74	883	547	336	520	326	194
ADULTS																								
22-64 YEARS	5,281	3,727	1,554	536	378	158	742	524	218	2,172	1,533	639	293	207	86	180	127	53	866	611	255	492	347	145
65+ YEARS	226	184	42	15	12	3	31	25	6	86	70	16	16	13	3	12	10	2	44	36	8	22	18	4
22+ TOTAL	5,507	3,911	1,596	551	390	161	773	549	224	2,258	1,603	655	309	220	89	192	137	55	910	647	263	514	365	149
TOTAL ALL AGES	11,899	7,113	3,530	1,392	799	412	1,637	987	490	4,588	2,779	1,364	680	406	201	431	257	129	2,026	1,194	599	1,145	691	343

FIGURE 2:

ESTIMATED NUMBER OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, BY AGE IN NEW MEXICO: 1990

	STATE			DISTRICT 1			DISTRICT 2			DISTRICT 3			DISTRICT 4			DISTRICT 5			DISTRICT 6			DISTRICT 7		
	DEV DISABILITIES			DEV DISABILITIES			DEV DISABILITIES			DEV DISABILITIES			DEV DISABILITIES			DEV DISABILITIES			DEV DISABILITIES			DEV DISABILITIES		
AGE GROUP	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER
INFANTS/PRESCHOOL																								
0-2 YEARS	479			68			60			168			27			16			96			44		
3-5 YEARS	879			125			112			310			49			30			173			80		
0-5 YEARS TOTAL	1,358			193			172			478			76			46			269			124		
SCHOOL AGE																								
6-17 YEARS	4,557	2,703	1,854	619	367	252	607	360	247	1,630	967	663	253	150	103	165	98	67	855	507	348	428	254	174
18-21 YEARS	986	732	254	120	89	31	125	93	32	373	277	96	57	42	15	35	26	9	166	123	43	110	82	28
6-21 YEARS TOTAL	5,543	3,435	2,108	739	456	283	732	453	279	2,003	1,244	759	310	192	118	200	124	76	1,021	630	391	538	336	202
ADULTS																								
22-64 YEARS	5,977	4,219	1,758	615	434	181	840	593	247	2,465	1,740	725	312	220	92	197	139	58	977	690	287	571	403	168
65+ YEARS	277	225	52	17	14	3	36	29	7	110	89	21	18	15	3	15	12	3	54	44	10	27	22	5
22+ TOTAL	6,254	4,444	1,810	632	448	104	876	622	254	2,575	1,829	746	330	235	95	212	151	61	1,031	734	297	598	425	173
TOTAL ALL AGES	13,155	7,879	3,918	1,564	904	467	1,700	1,075	533	5,056	3,073	1,505	716	427	213	458	275	137	2,321	1,364	688	1,260	761	375

FIGURE 3:

ESTIMATED NUMBER OF PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, BY AGE IN NEW MEXICO: 1995

	STATE DEV DISABILITIES			DISTRICT 1 DEV DISABILITIES			DISTRICT 2 DEV DISABILITIES			DISTRICT 3 DEV DISABILITIES			DISTRICT 4 DEV DISABILITIES			DISTRICT 5 DEV DISABILITIES			DISTRICT 6 DEV DISABILITIES			DISTRICT 7 DEV DISABILITIES		
AGE GROUP	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER	ALL	MR	OTHER
INFANTS/PRESCHOOL																								
0-2 YEARS	492			71			59			172			26			17			101			46		
3-5 YEARS	914			131			111			320			48			31			188			85		
0-5 YEARS TOTAL	1,406			202			170			492			74			48			289			131		
SCHOOL AGE																								
6-17 YEARS	5,023	2,979	2,044	702	416	286	649	385	264	1,780	1,056	724	273	162	111	167	99	68	988	586	402	464	275	189
18-21 YEARS	1,040	773	267	136	101	35	128	95	33	385	286	99	58	43	15	36	27	9	188	140	48	109	81	28
6-21 YEARS TOTAL	6,063	3,752	2,311	838	517	321	777	480	297	2,165	1,342	823	331	205	126	203	126	77	1,176	726	450	573	356	217
ADULTS																								
22-64 YEARS	6,396	4,657	1,939	708	500	208	919	649	279	2,710	1,913	797	331	234	97	208	147	61	1,088	768	320	632	446	186
65+ YEARS	321	260	61	21	17	4	41	33	8	128	104	24	20	16	4	17	14	3	62	50	12	32	26	6
22+ TOTAL	6,917	4,917	2,000	729	517	212	960	682	278	2,838	2,017	821	351	250	101	225	161	64	1,150	818	332	664	472	192
TOTAL ALL AGES	14,386	8,669	4,311	1,769	1,034	533	1,907	1,162	575	5,495	3,359	1,644	756	455	227	476	287	141	2,615	1,544	782	1,368	828	409

while the fewest live in districts 4 and 5.

Figure 5 depicts the relative proportions of the target population aged six and above who are classified as having either mental retardation or other developmental disabilities. As shown, the great majority are classified as having mental retardation (about 66%).

Figure 6 displays the relative percents of those with developmental disabilities by four age groups. These groupings correspond with key life stages (i.e., early childhood, school age, adult, senior citizen). As one would expect, significant proportions of the target population are school age (44%) or adults (43%).

Overall, these figures show that the estimated number of persons with developmental disabilities living in New Mexico will range from about 11,899 persons in 1985 to 14,386 persons in 1995. These figures suggest a prevalence rate of 0.81% (based on a state population of 1,462,884). About 66% of these persons aged six years and above will have mental retardation and most will be in school or of adult age.

B. The Present Demand for Services

1. Types of Demand

In assessing the probable demand for services by persons with developmental disabilities, it is important to distinguish between two types of service demand: expressed and unexpressed demand. Figure 7 shows these types of demand and their respective components under the general heading of potential or overall demand.

FIGURE 4:

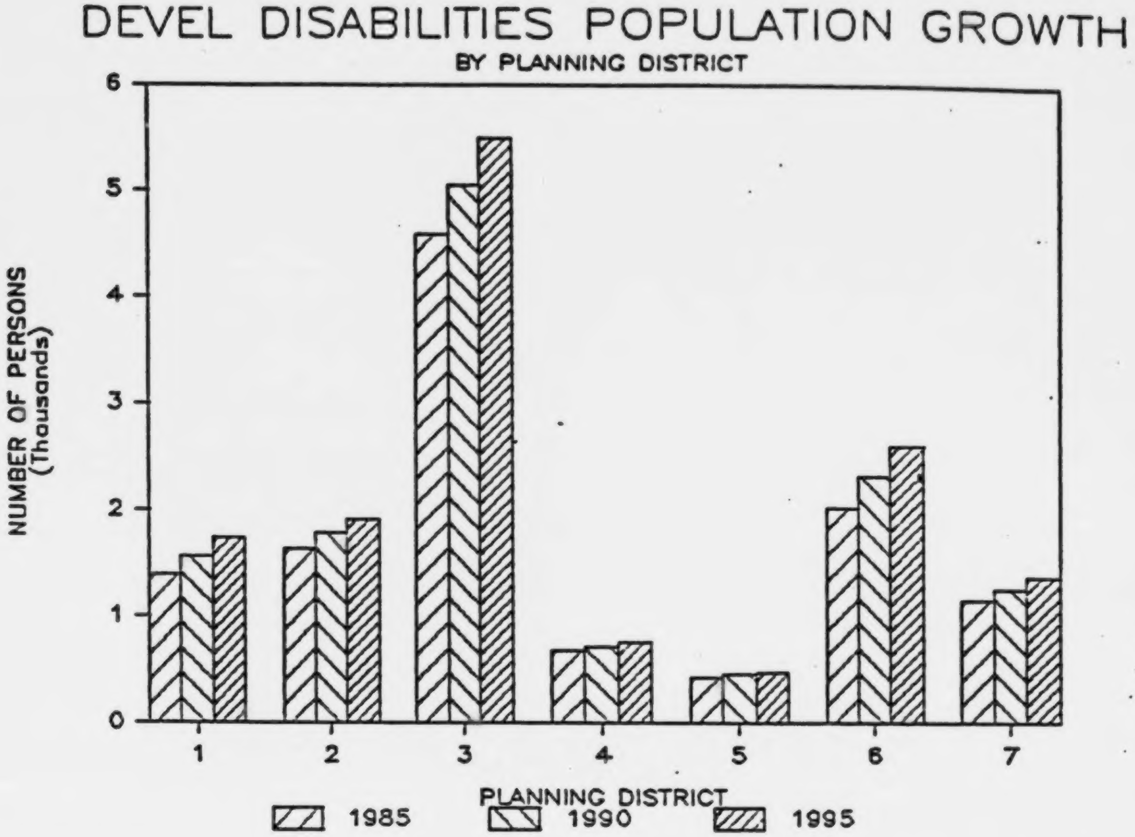

DEVEL DISABILITIES POPULATION GROWTH
BY PLANNING DISTRICT
NUMBER OF PERSONS
(Thousands)
0
1
2
3
4
5
6
1
2
3
4
5
6
7
PLANNING DISTRICT
▨ 1985
▧ 1990
▩ 1995

FIGURE 5:

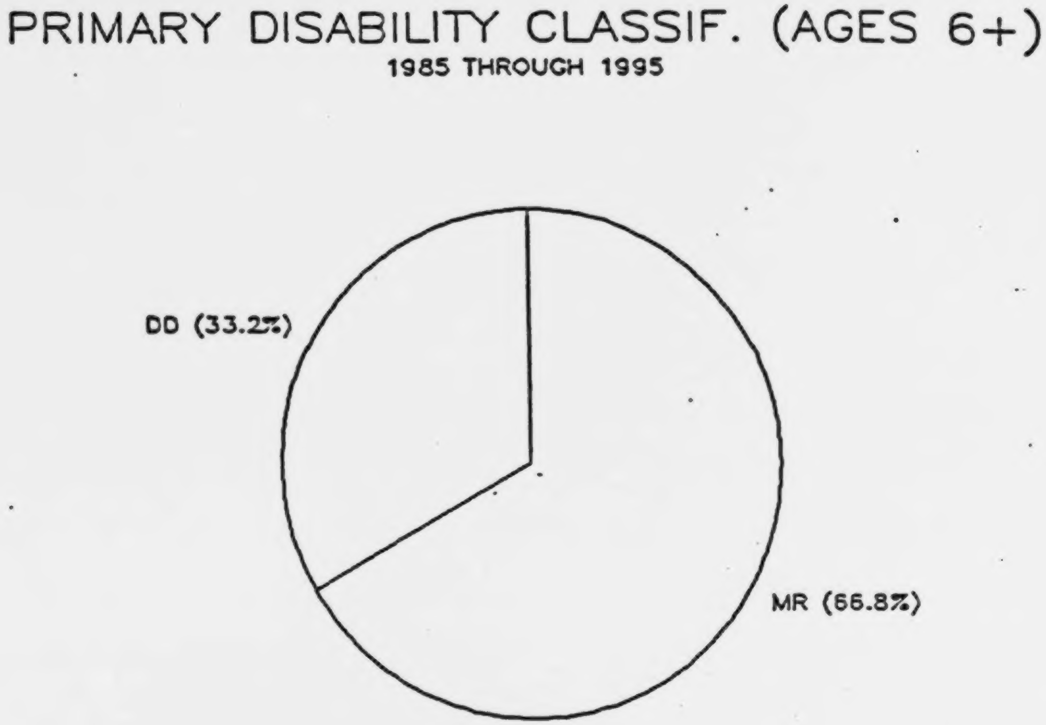


FIGURE 6:

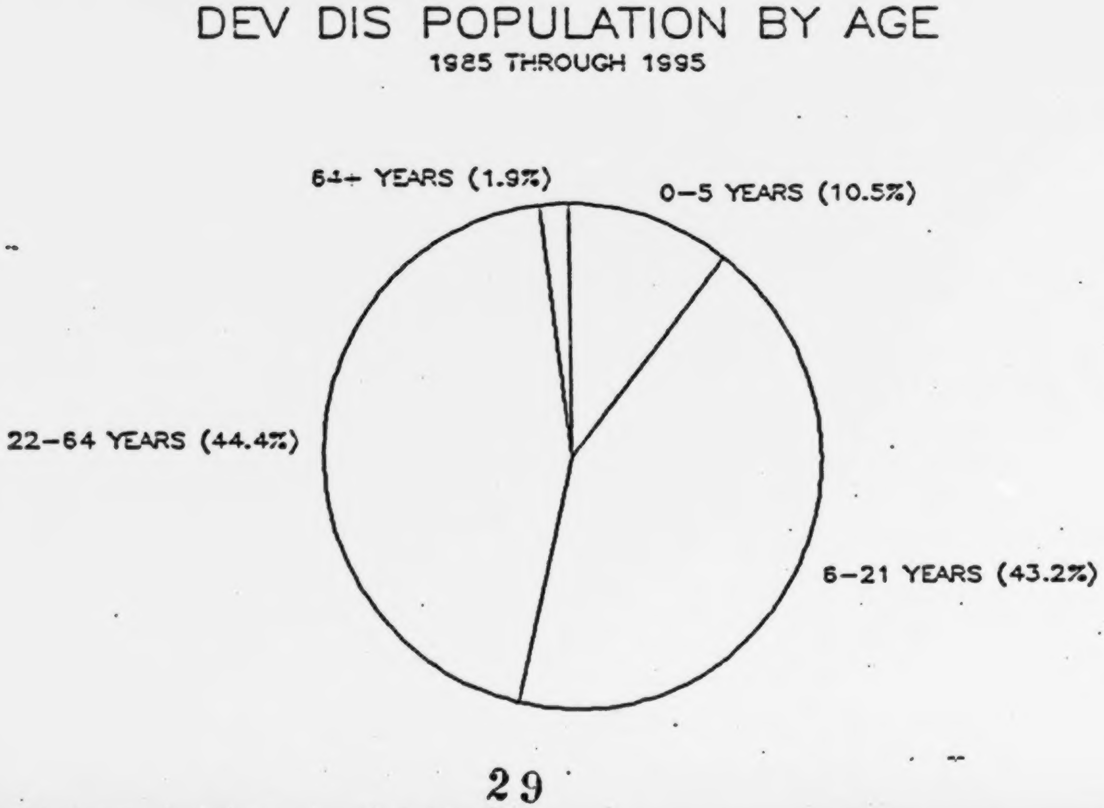
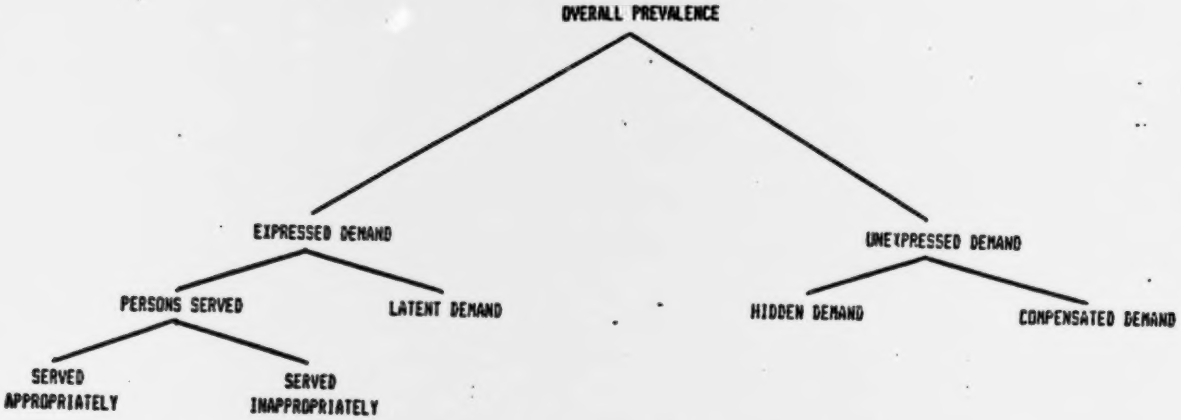


Figure 7: Types of Service Demand



These several demand categories are defined as follows:

- Potential demand: all persons meeting the target population definition (e.g., prevalence estimate);

- Expressed demand: the number of persons in the target population actually participating in service programs or known to the system due to an explicit request for services. There are three sub-categories:

  - * Those appropriately served. Persons in this category are receiving services appropriate to their functioning levels and needs; and

  - * Those inappropriately served. Persons in this category are receiving services, but some or all of these services are inappropriate, resulting in demand for other types or amounts of service; and

  - * Latent demand: Persons now demanding or requesting services but not receiving services. Such persons are found typically on waiting lists;

- Unexpressed demand: the number of persons not utilizing or demanding public services. There are two sub-categories:

  - * Hidden demand: persons not now demanding services but who would if they were available or had access to them; and

  - * Compensated demand: persons relying on private supports, and who would not presently demand public services even were they accessible and available. Given a change in the status of the private supports being used, these persons may well be reassigned to some other demand category.

We believe that planners could profit by devoting less attention to refining estimates of overall potential demand and more to improving estimates of latent demand and accomodating those who are served inappropriately. The proportion of the developmentally disabled population receiving publicly-supported services varies markedly from state to state in spite of the fact that the prevalence rates *per se* do not vary significantly from area to area. For instance, according to 1982 Census of Residential Facilities for mentally retarded citizens (Hauber, Bruininks, Hill, Lakin and White, 1984), Nevada reports only 34.2 beds per 100,000 population, while North Dakota reports 104.2. This distinct difference lends support to the notion that the level of utilization of publicly-funded residential alternatives is less affected by changes in the overall size of the developmentally disabled population (potential demand) than by changes in the supply of acceptable residential alternatives.

2. Source Data

To make a reasonable assessment of the service and related resource requirements of persons with developmental disabilities receiving services and awaiting services in New Mexico, HSRI divided the population into seven level-of-functioning categories: (1) serious medical and physical impairments, (2) moderate medical and physical impairments, (3) endangering behavior, (4) disruptive behavior, (5) minimally adaptive skills, (6) moderately adaptive skills, and (7) highly adaptive skills. (These categories are described in greater detail in an accompanying Appendix). Each of these categories was further divided into three age groups: (1) 0-5 years, (2) 6-21 years, and (3) 22 years and over. An individual could be assigned to one category only. Persons fitting into more than one category were assigned to the lowest (most dysfunctional) division.

Data were collected on the number of persons receiving services in each of the seven planning districts and at the two state intitutions by level-of-functioning, age, and by the type of residential and day (training) service(s) in which they were participating as of March 31, 1985. These data were obtained from two primary sources: (1) HSRI's mail/phone survey of 30 providers with contracts with the Developmental Disabilities Bureau (Health and Environment Department); and (2) the state's Client Oriented Option Profile (management information system). In addition, public forums were held in each of the seven planning districts to provide information that served as a check and complement to these data.

a. Provider Survey

The survey served two purposes:

(1) to obtain information that was not available from COOP, most importantly:

- a more detailed breakout of residential and training services;
- an assessment of the relative urgency of the situations of persons on waiting lists for services;
- the number of full time equivalent staff;
- the number of clients not registered in COOP; and

(2) to verify information available in COOP with regard to:

- the client levels of functioning (defined globally) -- the client level-of-functioning definitions and service definitions are shown as part of an accompanying Appendix.
- the number of clients receiving Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits.

b. Client Oriented Option Profile (COOP) Data

The COOP data were used in lieu of the HSRI survey for those few providers not responding to the HSRI survey, and for the two institutions. Clients were categorized into one of the seven levels-of-functioning using indicators available in the COOP data base.

Where COOP data and HSRI survey data were inconsistent, HSRI contacted the providers by phone for explanations. Twenty-two of the 30 providers responded to the survey. Not all responses were complete, and missing data could not always be obtained by phone.

c. District Planning Meetings

In some part, information gathered at these forums was used to check and complement provider and COOP data. HSRI conducted public forums in the seven state planning districts that were intended to attract family members, professionals, and others interested in the provision of services to persons with developmental disabilities. Mostly, they were held to solicit information regarding local needs for residential services, but participants were also asked to rank service needs in terms of their priority locally. The areas most commonly mentioned included the following:

- increased and improved residential opportunities for persons with severe and profound mental retardation, persons who are non-ambulatory and individuals with both mental retardation and behavior problems;

- adequate salaries to attract and retain residential staff;
- respite care for families who have maintained a family member with developmental disabilities at home;
- increased staff training opportunities;
- expanded "real world" work opportunities and job training programs for persons with developmental disabilities;
- increased vocational training programs in the public schools;
- training and support programs for families with developmentally disabled family members;
- greater public awareness of the needs and capabilities of persons with developmental disabilities.

Though attendance at the forums varied from district to district, the information gained provided a useful foundation for further data gathering. To augment and build on the information, forum reports were sent to an expanded group of district planning participants, and overview of the New Mexico developmental disabilities system was prepared and circulated, and district by district profiles were prepared which included information on current service utilization and demand and projections for future service requirements. These subsequent activities reinforced the need for increased living arrangements with a capacity to serve persons with more serious disabilities, and the need to provide expanded family support services, in addition to other system reforms.

d. Data Validity and Reliability

While the Provider Survey and COOP data on individuals in and awaiting developmental disabilities services in New Mexico are the best data available at this time, they are somewhat problematic. The method used to classify clients in this study has important limitations worth noting. The classification scheme, as designed, force fits clients with severe behavior, medical and physical disabilities into categories other than the categories distinguishing clients by adaptive skill level when in fact a client could fit into both types of categories. This was purposely done to identify the principal problem(s) that dictate client service requirements. However, resource limitations did not allow for the training of provider staff on how to complete the survey, and providers could not afford the time or were not inclined to spend a lot of time studying the written instructions. The resulting confusion, coupled with the inherent difficulty associated with making global judgements on client levels of functioning, put the validity of client classifications in some question.

Fortunately, the survey ratings of client levels of functioning that could be checked against the ratings computed from the COOP data were found to be quite consistent. The global survey ratings of clients were only slightly higher than the level-of-functioning ratings derived from the COOP data.

3. Overall Numbers of Persons Served and Unserved

Relatively few persons with developmental disabilities in New Mexico are served in out-of-home residential placements. Figure 8 shows that 1,038 persons, or about nine percent of the population, are served in such placements. In 1982, New Mexico ranked 42nd among the 50 states in terms of the number of publicly supported residential beds per 100,000 population.* New Mexico had 62 beds per 100,000 population; the average of all states was 105 per 100,000 population (Hauber, Bruininks, Hill and White, 1984). Based on our informal reading of the pace of residential program development in New Mexico and other states in the three years since, we expect that New Mexico's rank today would be about the same, perhaps slightly higher.

We suggest that there are at least two reasons for New Mexico's relatively low level of out-of-home placement:

- as with many rural states, the rate of admissions to institutional programs in years past was relatively low. In 1982 New Mexico's rate of persons in large residential facilities (over 64 beds) was little more than half that of the other states (Hauber et al., 1984); and
- The supply of residential placement alternatives has been limited.

Thus, relative to most other states, New Mexico relies heavily on private, family-based care. Nearly 92% of the estimated 12,000 persons with developmental disabilities reside at home. Clearly, this is to the considerable economic advantage to the state. Were New Mexico to have as many persons in out-of-home placements as the average state, another 600 beds would be required. At an ICF-MR institutional rate of $100 per day, this would add 22 million dollars to the annual cost of care for these individuals, almost 7 million dollars of which would be borne by

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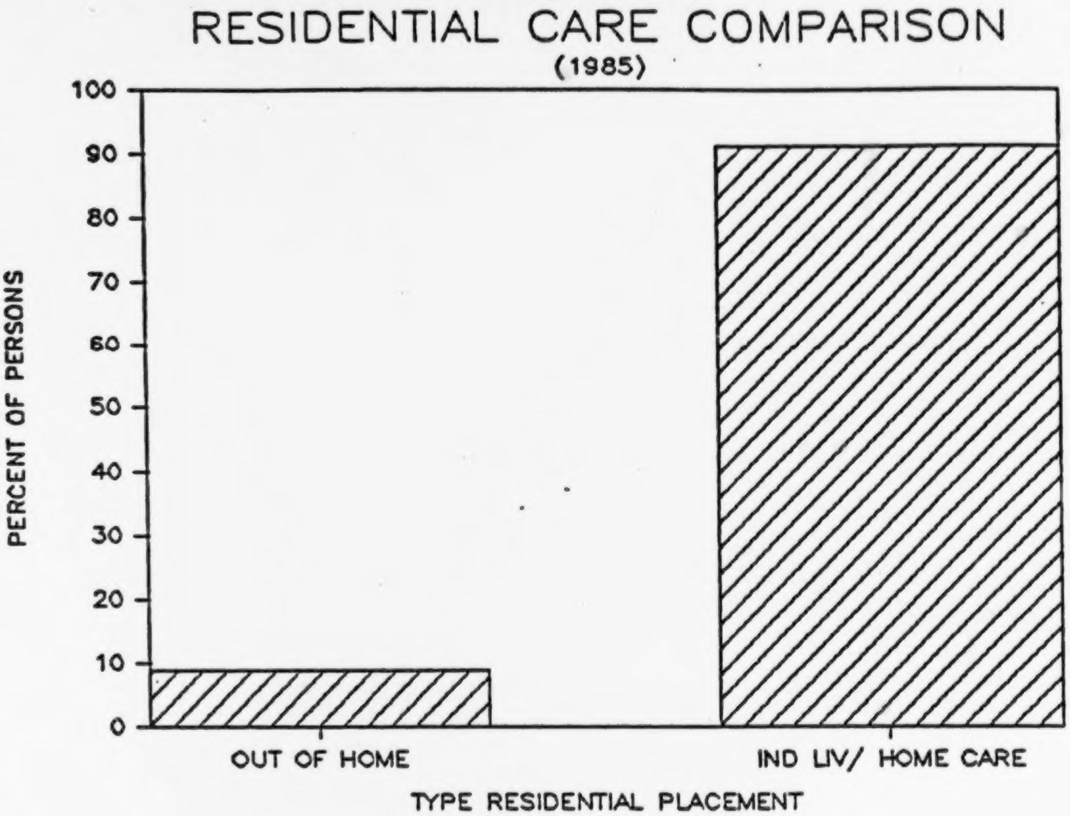
* Residential options are defined to include:— Parent/relative/guardian's home, Independent home or apartment, Dual residence (home/other), Foster care, Boarding home, Nursing home, Group home, and State institution.

FIGURE 8:


RESIDENTIAL CARE COMPARISON
(1985)
PERCENT OF PERSONS
100
90
80
70
60
50
40
30
20
10
0
OUT OF HOME
IND LIV/ HOME CARE
TYPE RESIDENTIAL PLACEMENT

the state. At the average community ICF-MR rate of $75, it would add another 16.5 million dollars to the annual cost of care, five million dollars of which would be borne by the state.

Regarding day placement, Figure 9 suggests that most, if not all, persons with developmental disabilities up to age 21 years receive day services. As shown, the number of persons receiving day services actually outnumber the total prevalence estimate for the 0-5 and 6-21 age groups. The primary reason for this is the inherent incompatibility of the public school data and information gathered during this study. Public school information tends to be more liberal in its criteria for determining the presence of a "disability," counting many persons who are not considered to have a "developmental disability." As a result the number of persons identified by the schools are much higher than those identified by HSRI through its prevalence estimates. Unfortunately, there is no way to make these data sets compatible. Even so, findings shown in Figure 9 imply that New Mexico provides a day program to a high percentage of its children with developmental disabilities. These findings, however, should not be taken at face value, given the obvious need to qualify these figures.

Many adults, however, are without a day program. In fact, Figure 9 shows that only 23% of those adults with developmental disabilities attend a day program. One may speculate that some proportion of the remaining 77% do not require a program, owing to private employment or some other mitigating factor. Yet, several persons attending the public forums commented that there is a chronic shortage of day programs for adults, suggesting these findings are reasonable and that state officials ought to set plans for building smoother transition between public schools and adult day programs.

Figure 9: Persons Attending Day Programs In New Mexico.

AGE RANGE	ESTIMATED PREVALENCE	# RECEIVING PRESCHOOL SERV	# RECEIVING SCHOOL SERV	# RECEIVING ADULT DAY SERV	# RECEIVING INSTIT SERV	TOTAL SERVED	PERCENT SERVED
0-5 YEARS OLD	1,248	897	1,179 *	0	64	2,140	171%**
6-21 YEARS OLD	5,144	0	5,880 *	0	195	6,075	118%**
22+ YEARS OLD	5,507	0	0	1,057	219	1,276	23%
TOTALS	11,899	897	7,059	1,057	478	9,491	

* SOURCE: DIVISION OF EDUCATIONAL SERVICES SPECIAL EDUCATION PROGRAMS (1985) SEVENTH ANNUAL REPORT TO CONGRESS ON THE IMPLEMENTATION OF THE EDUCATION OF THE HANDICAPPED ACT. WASHINGTON, DC: UNITED STATES DEPARTMENT OF EDUCATION.

** NOTE: THE SOURCE NOTED ABOVE INCLUDES IN ITS ESTIMATES PERSONS WITH DISABILITIES NOT CLASSIFIED AS HAVING A "DEVELOPMENTAL DISABILITY." THE PREVELENCE ESTIMATE, HOWEVER, IS FOR DEVELOPMENTAL DISABILITIES ONLY. AS A RESULT, WITH REGARD TO DEV DIS, THESE PERCENTS ARE LIKELY TO BE INFLATED.

4. Expressed Demand

As noted earlier, there are three types of expressed demand: persons served appropriately, persons served inappropriately, and persons on waiting lists (i.e., latent demand). Of the 1,038 persons receiving out-of-home residential care, HSRI concludes that many are presently served inappropriately. Additionally, the number of persons on existing waiting lists and the opinions expressed by various citizens at the public forums suggest that the latent demand for services is significant.

The largest number of publicly-supported residential placements are in institutional facilities and community group homes, 124 in community ICF-MRs, 440 in group homes and other residences, and another 474 in institutional settings. Minimal supervision residential models (such as minimally supervised apartments and companion homes) are limited or nonexistent in most districts. As one might expect, the lack of a residential continuum is most apparent in less populous districts such as District 1 and District 7.

Overall, there appears to be a satisfactory balance between the level of functioning of clients in residential placements and the level of supervision provided. In some districts, however, the initial profiles suggest that some persons with relatively less severe disabilities are being served in overly restrictive supervised settings.

Moreover, as shown in Figure 10, while group home staff/client ratios and day program staff/client ratios appear adequate compared to staffing standards and norms of like programs in other states, these care givers are reportedly provided few supports (e.g., staff training; specialist consultations on how to manage clients with behavioral, physical, and medical problems; funds for structural adaptations to accomodate persons with physical impairments; specialized diagnostic and evaluation services; and crisis support services in the event of unmanageable behaviors). As a result, even where persons with disabilities seem properly placed, the services they receive could be improved, if staff were accorded the training and supports

FIGURE 10:

STAFF TO CLIENT RATIOS BY TYPE OF PROGRAM

PROGRAM TYPE	New Mexico Programs (Median)[1]	Program Standards and Models (Range)[2]
Residential		
ICF-MR (N=2)	2.7	2.0 - 8.0
Residential -- Moderate Supervision (N=5)	2.1	1.2 - 10.6
Residential -- Minimum Supervision (N=7)	8.5	8.0 - 17.3
Day		
Work Activity Centers	7.2	5.0 - 20.0
Adult Day Habilitation	5.0	4.0 - 5.0
Sheltered Workshops	5.2	5.0 - 20.0

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[1] Source: HSRI Provider Survey

[2] Source: HSRI Multi-State Survey of Program Staffing Standards and Models

required to enhance their ability to provide superior care.

a. Inappropriate Placements

HSRI concludes that significant numbers of those presently served in out-of-home residential options are living in situations considered to be age inappropriate, too restrictive, not sufficiently accessible, or for whom alternative circumstances are desired or necessary.

- For reason of inappropriate placement due to age. In part, the least restrictive alternative principle requires that a living situation reflect an age and culturally appropriate environment that accommdates the individual's need for supervision and training. Regarding children, current theory in the field holds that the family unit is the most desireable and effective residential option. As a result, to serve children require placement away from the natural family, many states vigorously pursue development of alternative family like options (e.g., foster homes, small community residences). Such options have been developed for children with varying levels of disability, including those with severe handicapping conditions.

  In this light, placement of children in institutions, especially Los Lunas, is deemed inappropriate. Figure 11 shows that 33% of those at Los Lunas are under 21 years old, with eight under 5 years. Overall there are about as many children aged 0-21 living at either Los Lunas (n=113) or Fort Stanton (n=13) than in all other types of community residences combined (n=143). The Institute recommends that New Mexico make provisions for serving its children with disabilities in options other than the institution.

Figure 11: Residential Placement of Persons with Developmental Disabilities in New Mexico

		AGE GROUP		
RESIDENTIAL PLACEMENT	ALL AGES	0-5 YEARS	6-21 YEARS	22+ YEARS
COMMUNITY RESIDENCES	564	32	111	421
FORT STANTON	127	0	13	114
LOS LUNAS	351	64	182	105
INDEP LIVING/ HOME CARE	10,857	1,152	4,838	4,867
TOTAL WITH DEV DIS (1985)	11,899	1,248	5,144	5,507

NOTE: THE 32 PERSONS 0-5 YEARS LISTED AS LIVING IN COMMUNITY RESIDENCES ARE ALL IN FOSTER CARE

- For reason of overly restrictive care. Again consider that the least restrictive alternative principle requires that individuals be provided a living situation that meets the person's needs for supervision and training without compromising personal rights. Assuming that persons with overriding severe medical, physical, and behavioral problems or minimum self care skills require high supervision, and others, moderate to minimum supervision, most individuals are in appropriately supervised residential and day activities in New Mexico.

  However, by our analysis, approximately 50 clients (those with disruptive behaviors and moderate or high levels of daily living skills) now in ICF-MR or other high supervision facilities could benefit from moderately supervised arrangements.* Added to this number are a 177 persons who are presently served in community residences, but who are on waiting lists for more appropriate placement.

- For reasons of size and segregation. As a rule, the impersonal, bureaucratic organizational structures and management procedures associated with large, centralized providers of care, tend to impede rather than promote the personal interaction, support, flexibility, and esprit de corps necessary for motivated and effective residential caregivers. As important, larger programs tend to be more standardized and uniform compared to smaller settings where staff can be more sensitive to individual client needs. Counteracting factors that argue in favor of large versus small programs for particular types of clients are absent; moreover, there are few economies of scale associated with large, labor-intensive developmental disabilities services (Ashbaugh, 1984).

  Accordingly, in the Institute's judgement, the 127 clients at Fort Stanton should be moved into community settings as soon as possible. With respect to Los Lunas, we have already noted that the movement of the children to home-like environments should be a high priority. We also suggest that the long-term future of Los Lunas be seriously scrutinized.

b. Persons on Residential Care Waiting Lists

Overall, HSRI estimates that 460 persons are awaiting placement in alternative settings. Figure 12 shows the number of persons on waiting lists for residential or institutional placement by age, if known. In this figure and the accompanying bar graph, most of these persons are over 22 years old and are requesting community placement. Figure 13 and its accompanying bar graph display the type of placement requested by the source of the request. Most current requests appear to be coming from persons already in community placements.

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* A small number of these persons should be counted in the 158 persons identified by providers as inappropriately placed and on the community waiting list.

As depicted in Figures 12 and 13, 312 persons not presently in institutions were identified by community providers as needing a group home placement as of June 1985. However, information on the level of functioning of these individuals is insufficient to judge the level of residential supervision and supports required, and no information is available on the relative urgency of their situations -- that is, reflective of the burden being placed on the private care givers and the present adequacy of these supports considering the clients' health, safety and welfare.

Though responses to HSRI's provider survey relating to the urgency of residential placement requests were incomplete, those 11 providers completing this part of the survey indicated that 15% of the non-institutionalized persons wait-listed were in urgent situations, that is, judged to be in circumstances posing an immediate threat to their health or safety. Another 28% were in inadequate residential situations -- inadequate in terms of the quality of the food, shelter, clothing, care and treatment, privacy afforded, and in terms of the dignity and respect shown them. Assuming that these 11 providers are representative of all group home providers, 48 of the 312 clients were in urgent

FIGURE 1 2

AWAITING PLACEMENT IN	ALL AGES	AGE GROUP 0-5 YEARS	6-21 YEARS	22+ YEARS	UNKNOWN
COMMUNITY RESIDENCES	395	4	50	258	83
FORT STANTON	0	0	0	0	0
LOS LUNAS	65	9	41	15	0
TOTALS	460	13	91	273	83

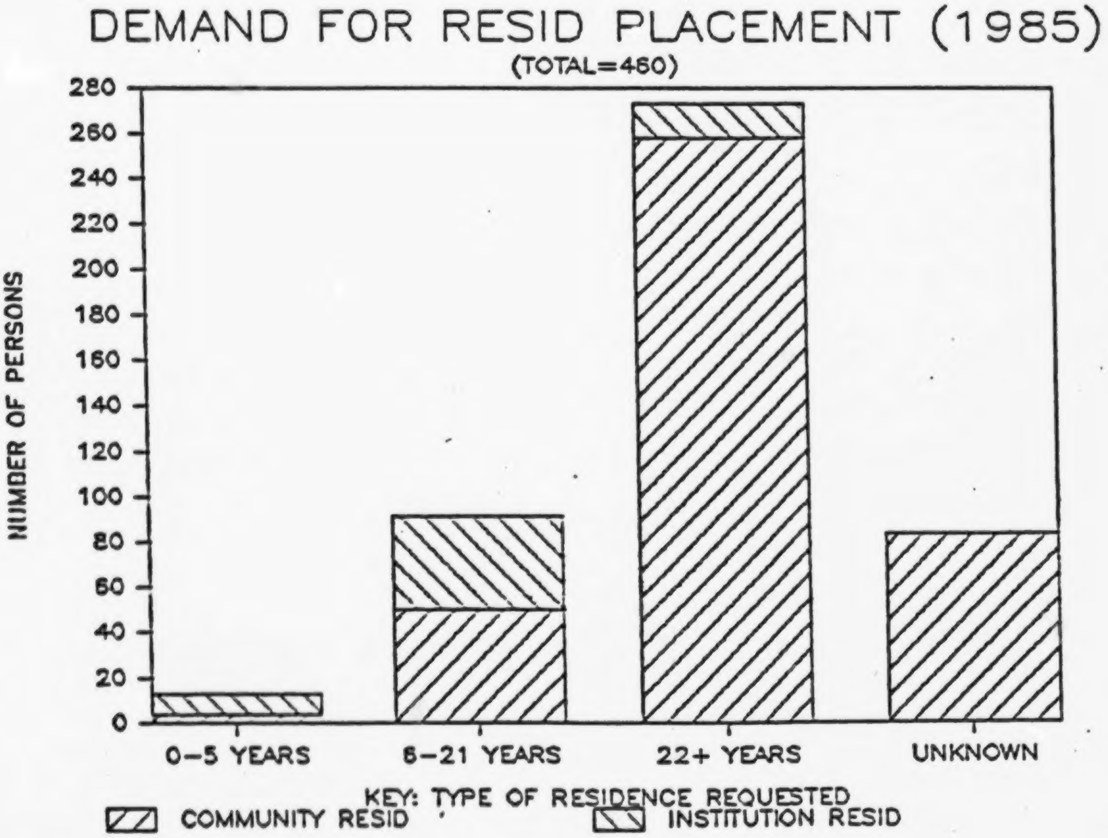
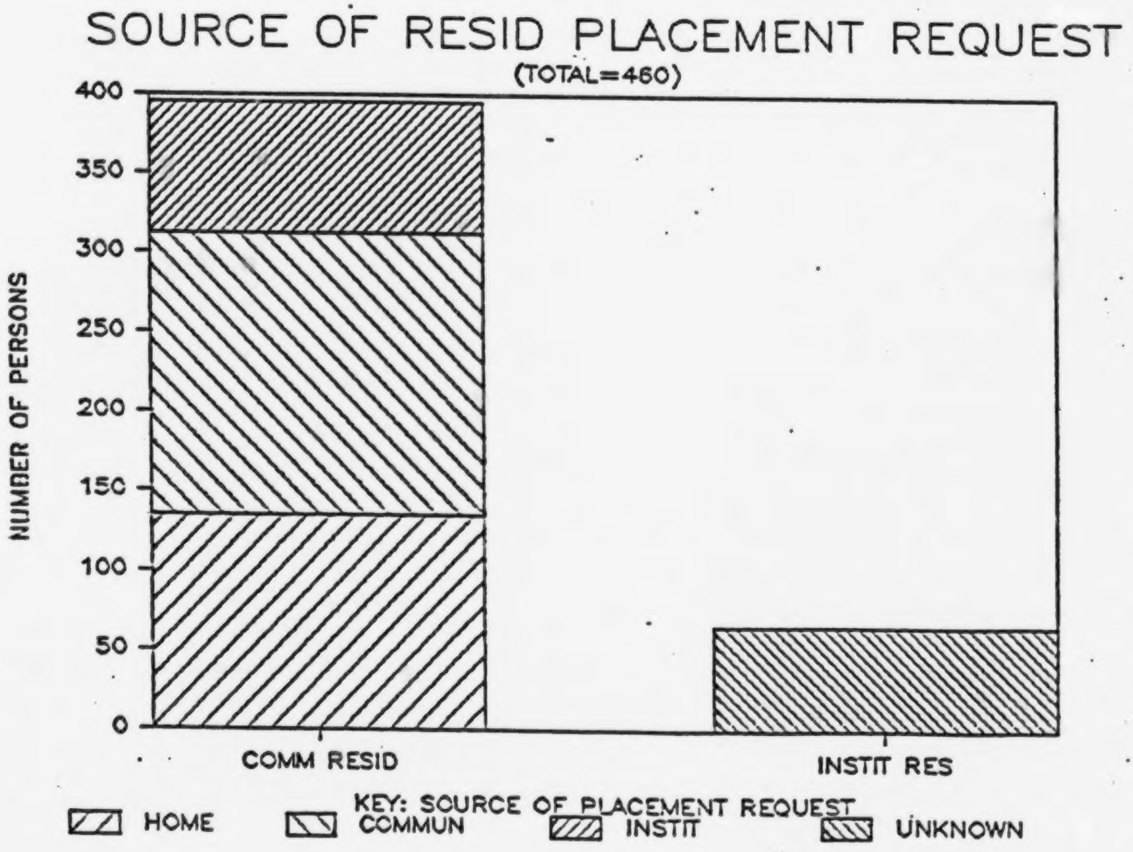


FIGURE 13

		SOURCE OF PLACEMENT REQUEST			
AWAITING PLACEMENT IN	ALL SOURCES	HOME CARE	COMM RESIDENCES	FT STAN & LOS LUNAS	UNKNOWN
COMMUNITY RESIDENCES	395	135	177	83	0
FORT STANTON	0	0	0	0	0
LOS LUNAS	65	0	0	0	65
TOTALS	460	135	177	83	65



situations and 87, in inadequate situations.

In addition to these 312 persons, another 83 persons presently in institutions are awaiting community placement. Conceivably, these persons are considered capable of performing well within current community settings.

Finally, another 65 persons are awaiting placement in Los Lunas. It is unclear to HSRI whether these persons are currently living at home or in community residences, but most (N=50) are under 21 years of age.

C. Estimate Qualifications

While the COOP data, data from the HSRI survey, and information gathered at the district planning meetings were sufficient to identify the obvious and immediate demand for residential and support services, they provide an inadequate base for ongoing longterm planning. The waiting-list data are incomplete. Such lists will be representative and complete only when all prospective applicants for residential services in New Mexico are aware of the lists and understand that they must be listed as a prerequisite to receiving service. At present the information on the clients is not sufficient to discriminate individuals by level of functioning and corresponding service requirements, nor by the urgency of their present situations.

Accordingly, the Institute strongly recommends that the Developmental Disabilities Planning Council, in fulfilling its legislated mandate to assess the need for developmental disabilities services in New Mexico, design, develop, and implement a data collection system designed to assess the functioning level and needs of persons already receiving services, as well as those applying for services.

5. Unexpressed Service Demand

The developmentally disabled population includes a number of persons who have not demanded publicly supported services, some of whom would demand appropriate services if they were available (hidden demand). Some, however, would not (compensated demand). The latter group is presently relying on private residential services or supports.

It is important to recognize that additional expressed demand will surface as new residential and related support services are established to accommodate present service needs. This increased demand is generated by virtue of the added visibility and accessibility of these services, and the implicit message that such alternatives represent available and acceptable alternatives to family caregivers. In other words, the level of hidden versus compensated demand is not only a function of the adequacy of private residential services and supports, but of the availability of acceptable alternatives.

The state, as a marketer of residential services, has the ability to generate and shape residential demand. Forty years ago demand for residential services was channeled into institutions. More recently New Mexico, like most other states, has begun to channel this demand into community residences. In future years, respite care and other family support services hold promise to redirect some of this residential service demand into residential supports for those families seeking relief and support rather than separate residential arrangements for their dependents with disabilities.

As shown earlier, the great majority of persons with developmental disabilities are not provided residential care through the present service system. Rather, these persons live on their own or, more likely, reside with their families.

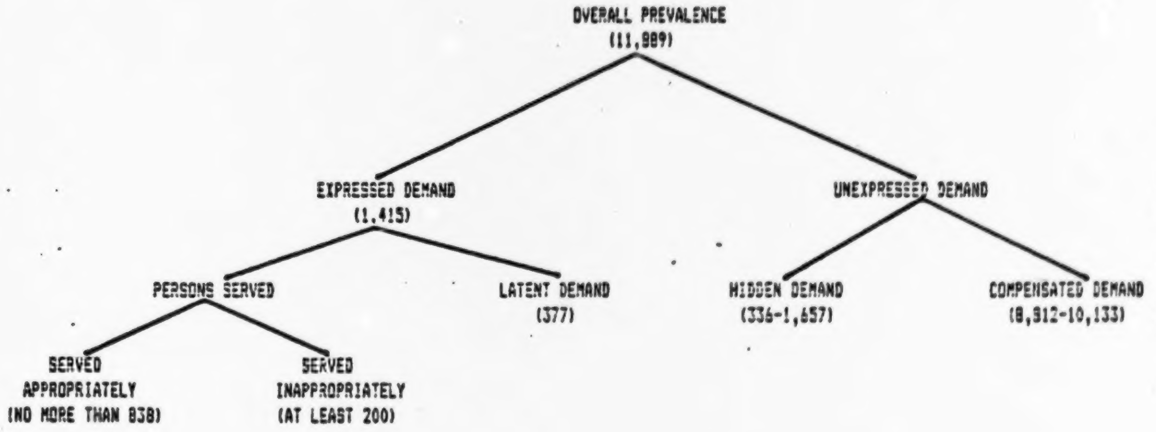
Yet, the state provides little support to these families. Less than one percent (71) of these families receive family support services and then only respite care; most of these families live in the Albuquerque area and utilize the Los Lunas respite program. Respite care and other family support services are not offered. Examples of the types of services that should be available depending on individual family circumstances, include adaptive equipment, educational/therapeutic services, transportation, medical or dental services, home barrier removal, special clothing, special diets, diagnosis and assessment, medication, home health care, attendant care, recreational services, information and referral, temporary relief/respite, family counseling, parent/sibling education, homemaker services, chore services, housekeepers, cash assistance, and future financial planning. Thus, it seems reasonable that if families who provide home care were provided needed supports, the state could assure that the expressed demand for more expensive out-of-home placements would remain minimal, even in face of an expanded residential continuum. Moreover, the provision of family supports, while relieving care related stresses, would enhance the quality of the home care provided, benefiting all concerned parties.

Reasonably accurate assessments of the hidden demand associated with different service alternatives are best made from studying service supply/demand relationships over a period of years using a systematic determination system. In the absence of these data it is possible only to make outside estimates of hidden demand using comparative demand figures from other states. Under the conservative assumption that the ratio of expressed demand plus hidden demand to potential demand in New Mexico equals the average ratio of expressed demand (number of persons in service or wait-listed) to potential demand in the other 49 states, the hidden demand would total 336 persons. Under the liberal assumption that the ratio of expressed demand plus hidden demand to potential demand in that state reporting the highest such ratio, the hidden demand would total 1,657 persons. These comparative data are based on the 1982 National Census of Residential Facilities (Hauber, Bruininks, Hill, Lakin and White, 1984).

6. Summary of Service Demand by Demand Type

Figure 14 summarizes the estimated demand for residential services for persons with developmental disabilities in New Mexico in 1985 by category of demand.

Figure 14: Types of Service Demand*



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* Those served total 1,038. Of this number at least 200 are served inappropriately, including 127 persons at Fort Stanton and 73 persons at Los Lunas.

IV. OVERVIEW OF THE STATE SERVICE SYSTEM FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

A. Introduction

At first glance, the provison of residential services to persons with developmental disabilities in New Mexico appears to be influenced by a wide variety of obstacles. However, a closer look reveals that there are a few central or leading issues that significantly shape the current system. The following section attempts to identify these central issues and show how they are viewed by persons familiar with current and past efforts to design and use residential services in the state.

Information for this portion of the analysis was obtained from interviews with key persons in the New Mexico developmental disabilities system, and reviews of state plans, budgets, reports, and studies relevant to residential services.

B. Recent Trends in Residential Services

Since the late 1970s, residential services for persons with developmental disabilities have been the focus of a lot of attention in New Mexico. The changes that have occurred have benefitted persons needing residential services and have facilitated the efforts of administrators responsible for developing appropriate services. Some of these changes and trends are as follows:

- Community programs have been growing at a rate faster than institutions;
- Automated management information systems give a more accurate picture of expenditures, and number of persons benefitting from services;
- For the first time, there is evidence that the legislature and other decision makers support services to

families with a developmentally disabled relative.

In 1977 the state's Mental Health and Developmental Disabilities Code was passed which stimulated much of the reform. The act outlined the rights of clients and required that treatment be provided in the least restrictive environment appropriate to their needs. Further the Governor's 1983 policy statement on the disabled emphasized enhancement of community-based care, accessibility and rights, family-centered services for the "chronically disabled," deinstitutionalization of persons who can be served in less restrictive settings, and a greater emphasis on prevention and early intervention.

In the Developmental Disabilities Community Services Act, enacted in 1984 by the legislature, priority was given to the development of community based services for persons with developmental disabilities to enable them to live as independently and productively as possible. The Act also provides a uniform definition of developmental disabilities and specifies the responsibility for planning and providing services by state government.

Other legislative and executive response to the residential needs of the persons with developmental disabilities in the past few years are included in Table 1 on the next page which lists state appropriations for new programs both in the community and in institutions.

Not all legislative requests have been successful. In 1981 a $7 million dollar request for group home construction died at adjournment. Numerous cost-of-living increases for community programs have been cut in many of the past few years to only one to two percent.

The total amount of funding for community programs and institutions for persons with developmental disabilities is summarized in Table 2. The number of persons living in these programs is outlined in Table 3. This latter table also shows the growth in recent years in the continuum of residential services in New Mexico.

The information in Table 3 tells us that approximately 50% of persons with developmental disabilities residing outside their homes are receiving a hospital or institutional level of care. Institutions, however, receive twice the level of funding that is received by community programs. In addition, at least $2.5 million in state funding has been appropriated for capital improvements in the past three years to the institutions. Considering that virtually no capital has been appropriated to community programs, the cost borne by the state for institutional care compared to community-based care is significant.

Table 1

1980-81	Deinstitutionalization project	$500,000
	new program - Raton, NM	54,000
1981-1982	Program expansion - Gallup and Coyote Canyon, NM	100,000
	Residential expansion (other community)	418,000
	Capital Projects - Los Lunas	Not available
	Capital Projects - Fort Stanton	1,326,000
1982-83	Early chilhood community based services	332,000
	Capital projects - Los Lunas	Not available
	Capital projects - Fort Stanton	965,000
1983-84	Residential contingency (for 11 group home operations includes $400,000 match for Medicaid waiver	673,000
	Capital projects - Los Lunas	211,000
	Capital projects - Fort Stanton	880,000
1984-85	Medically fragile children's program (partially used as match for Medicaid waiver	200,000
	Early childhood services	202,000
	Residential contingency (in addition to prior year's appropriation)	527,000
	Capital projects - El Mirador*	225,000
	Capital projects - Los Lunas	280,000
	Capital projects - Fort Stanton	-0-
1985-86	Community residential expansion	850,000

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* El Mirador is the only community program providing resdidential services using state-owned facilities; $270,000 additional was awarded by the New Mexico Board of Finance

Table 2

Revenue Totals for Residential Services for the Developmentally Disabled

Year	Institutions*	Community Programs	TOTAL
1983-84	$21,489,100	$8,302,500	$29,791,000
1984-85	19,532,800	10,316,473*	29,849,173
1985-86	19,482,600	10,256,000**	29,739,000

* Includes developmental disabilities Medicaid Waiver projected Title 19 reimbursement; does not include federal reimbursement for Medically Fragile Children's Program.

** Budget shows a reduction because of reversion of unspent expansion funds and transfer of one service program to another.

Table 3

Persons With Developmental Disabilities in Residential Services in New Mexico*

Residential Arrangement	1982-1983	1983-1984	1984-1985***
Institution	496	487	493
Community ICF/MR		70	78
Group Home		298	307
Independent Living/ Transition		57	147
Specialized Foster Care/ Companion Home		27	40
Total Community	315	452	572
Total All Residential	811	939	1065

* Based on figures from the Developmental Disabilities Bureau

** No breakdowns by type of residence available for 1982-1983.

*** These figures differ from those used elsewhere in the text since they are for a earlier reporting period.

Finally a new unit price system, went into effect in 1984 to finance community programs. The system makes no differentiation between work-related and other day services, also known as adult day care and activities programs. As with the implementation of any new method of reimbursing services, the unit price system has experienced numerous problems. Concerns were expressed by providers that rates do not reflect the true costs of providing services. Some programs are not receiving the rate established by HED, therefore providers took their concerns directly to the 1985 Legislature with a $400,000 request for unit price "equity." The request was not granted but the budget committee report included language directing HED to look for money to equalize the impact of the new reimbursement scheme within the agency's budget.

C. Deinstitutionalization and Expansion of Community Services

The New Mexico Legislature recently responded to the attempt by the Cabinet Secretary of HED to close Fort Stanton by enacting the following (1984, Chap 7):

> ...the appropriation...is contingent upon the Department making full utilization of the facilities at Fort Stanton Hospital and Training School as necessary for developmental disabilities respite of residential care to eliminate waiting lists at the Los Lunas Hospital and Training School and for other individuals diagnosed to require such services.

Announced by the Cabinet Secretary of HED in July 1983, the transfer of clients to community programs was already underway when this legislation halted closure. Early in 1984 a task force was appointed to make recommendations about the long-term use of Fort Stanton in response to the legislation halting its closure. One of the major recommendations growing out of the task force was the necessity of developing a residential plan that provided for persons inappropriately placed in Los Lunas and Fort Stanton, persons on waiting lists in the community and persons who will be requesting residential services in the future. It is worth noting that between 1976 and 1983 Fort Stanton had already undergone a significant reduction in population from 221 to 138. In part this was due to numerous court orders that ruled that Fort Stanton was a more restrictive environment than was necessary for many Fort Stanton residents (as mandated by the MH/DD code). Today there are still court orders outstanding on approximately 50 persons at Fort Stanton. Another 20 are waiting community placement under court order at Los Lunas. The staff at Los Lunas identified another 50 persons who do not need an institutional level of care.

In addition to court orders, federal initiatives have also facilitated the move to community and family based services. The federal approval of New Mexico's Medicaid waiver in 1983 (which allowed the state to use Medicaid funds for institutional alternatives as long as New Mexico could show a net savings over projected institutional costs) made it possible for institutional clients to receive Medicaid funding in community homes. However, in order to keep its waiver, the state must show that the total number of ICF/MR beds is not increasing.

The development of ICF/MR beds requires that providers obtain approval from the State Health Planning and Development Agency (SHPDA) in HED. Until 1983 this was done by issuing a "Certificate of Need (CON)." In 1983, however, the legislature discontinued the CON provisions and the SHPDA began to rely on the health planning provisions of Section 1122 of the Social Security Act to limit growth. The provisions of Section 1122, however, do not have as much "clout" in the case of agencies that have purchased or renovated their facilities with private donations. In addition, the advisory board to the SHPDA -- the State Health Coordinating Council (SHCC) -- placed a "cap" on the number of ICF/MR beds, allowing for no increase since July 1983.

New Mexico has been successful in closing one institution, Villa Solano. The initiative to close the facility near Roswell in 1982 met with considerable local resistance at the time. Thirty-three of the 49 residents were transferred to nearby community programs, with the remainder sent to Fort Stanton. A two year follow-up of many of these clients in community programs shows that they have made significant progress in their skill levels.

As seen by the legislative action to halt closure of Fort Stanton, local politics and economics, as well as the concerns of parents who support institutional placement for their children have a strong influence on the direction of residential services in New Mexico.

D. Trends in Other Service Areas

Other initiatives by advocates and consumers to expand service availability include several class action suits. The state Association for Retarded Citizens played a key role in a suit that claimed that the public schools were not meeting the legislative requirement that all children receive special education services who needed them. Settled in 1982, this suit had a substantial impact on the provision of services to children with severe handicaps. Consumer representatives have also successfully obtained legislative appropriations for additional services. It was a consumer-backed bill that provided family-centered services for medically-fragile children in 1984.

One of the services that is available to families in need of temporary relief from caregiver responsibilities is respite care. Specific respite services available through the Developmental Disabilities Bureau are as follows:

- 623 days to 31 persons at Los Lunas (1983-84 data);
- 155 days to 5 persons at Fort Stanton (1983-84 data which is expected to double in 1984-85);
- Approximately 50,000 hours to 200 persons in community programs; expected to increase by 60+ persons by July 1985).

Carrie Tingley Hospital (CTH) began providing respite care for medically fragile and orthopedically impaired children in the Spring of 1984. Two beds are currently avaiable at CTH for respite, and they will be expanding the program to include respirator dependent children by late 1985, a need not presently met elsewhere in the state.

The special education budget in the Department of Education constitutes the largest single source of day programs for persons with developmental disabilities. The special education budget is $82 million. A total of 32,000 students are enrolled in special education programs. Of those, 4,000 students are in "D level" programs, the most intensive special education service. Approximately 350 of these children were served in state-supported institutions. The method used by the Department of Education for classifying children does not allow for the identification of the number of developmentally disabled children that are enrolled in special education.

The number of special education graduates likely to be needing adult services by 1990 was projected in a study conducted by Southwest Research Associates in 1981. They found that over a ten year period (to 1990), 1170 "C" and "D" level graduates will need sheltered workshop services. The year 1990 will be a high water mark with approximately 200 persons with disabilities graduating from high school. It was also found that the mean income of C and D level graduates was less than $150 month and that 66% were living with parents and were totally dependent on them for support.

The state Division of Vocational Rehabilitation (DVR), also located in the Department of Education has in recent years shifted its emphasis to serving persons with more severe handicaps in response to Congressional changes in the Federal Rehabilitation Act. In 1983-84, DVR states that 60.8% of those who were successfully rehabilitated were severely disabled. Although DVR does not categorize its clients so that persons with developmental disabilities can be identified, it is not likely that many are served by DVR. Of 7,237 clients served, 230 were mentally retarded and only 66 had been in public school special education.

The leading provider of adult day services in New Mexico is the Developmental Disabilities Bureau, HED. In fiscal year 1983-84, approximately 800 clients were served in work-related and other day programs in the community. In fiscal year 1984-85, this number is expected to increase to 928. According to a Bureau report prepared in mid-1984, 125 clients in adult day programs in the community completed their programs and moved to more appropriate placements over a two-year period. Total client wages paid to clients in sheltered employment amounted to:

Year	Wages
1981-82	$216,830
1982-83	$275,802
1983-84	$501,372

E. Service Indicators

Descriptions of client circumstances are described in the 1983-86 State Plan of the Developmental Disabilities Council as follows:

- 90% of the entire population of persons with developmental disabilities live in parent/family homes; of those over 18 years of age, 35% remain at home;
- state institutions house nearly 25% of the population and 80% of them over 18 years old;
- individuals classified as living independently make up less than 5% of the population; persons in foster care represents less than 2% of the total;
- of the residents of group homes 75% are classified as functioning at the mild level or above.

Persons with two or more disabilities make up the majority of the population at the institution. Table 4 shows that Los Lunas has significantly more persons with two or more disabilities than Fort Stanton, and in general serves persons with more severe handicaps.

Table 4

Nature of Disabilities in New Mexico Institutions

Fort Stanton Population

58% have two or more disabilities
75% are severe/profoundly handicapped
22% are moderately handicapped
2% are mildy handicapped
0% are at risk

Los Lunas Population

85% have two or more disabilities
91% are severe/profoundly handicapped
5% are moderately handicapped
2% are mildly handicapped
2% are unknown/at risk

(Source: DD Bureau, HED annual report, 1983-84)

The institutions report that 65 persons who are considered appropriate referrals are on the waiting list for placement in Los Lunas or Fort Stanton as of January 1985. The majority of referrals are reportedly persons with dual diagnoses.

A special unit for persons with developmental disabilities as well as serious mental health problems was established at Los Lunas in 1983 in response to the Montano v. Goldstein lawsuit which outlined the state's responsibility for serving these persons. The unit houses approximately 20 persons.

In community programs, only 35% of the persons served have two or more disabilities. These programs generally do not provide a special unit or seperate service program for persons with a dual diagnosis (mental health and mental retardation). It is these persons described as the most difficult to place in the community and they are occasionally referred back to the institutional setting. A state plan that addresses the needs of the dual diagnosis population could not be found.

F. Administrative and Organizational Factors

Frequently changing leadership in HED, with four Cabinet Secretaries in four years, has contributed to the lack of continuity in developmental disabilities services. In 1984, for instance, the leadership questioned the need for existing services and proposed a 10% cut to all behavioral health services, including the Developmental Disabilities Bureau, that could not be justified. This effort to cut back on spending in HED also led to a "freeze" in hiring for the better part of a year, resulting in a staff shortage in HED. Consequently, fewer site visits to monitor community programs were conducted than in the previous year.

In 1979 the Residential Treatment Division was created in HED and the institutions were placed under a separate administration. In 1983, the institutions for persons with developmental disabilities were moved under the Developmental Disabilities Bureau, creating a joint administrative entity. This facilitated greater interaction and sharing between the community and institutional sectors. For example, physicians at the institution spent a day a month in community programs and waiting list data reflected the needs across the continuum of service without duplication of clients. Most recently, however, these two functions have again been separated.

Attempts to develop regional services have not met with much success in New Mexico. Although a few programs have merged in recent years, most entities were created without regional coverage in mind. Multiple programs exist in Hobbs, Albuquerque and Alamogordo. In 1980, HED formed technical advisory groups (TAGS) which were intended to conduct regional planning in seven districts. These short lived groups lasted one year, at which time the funds reportedly were reallocated to direct services.

G. Summary

In conclusion it should be pointed out that New Mexico has made progress in providing appropriate residential and support services. Examples include the increased capacity of community placements, the implementation of standards for monitoring and guiding community programs, and the recent legislation providing family centered services to medically fragile children -- a population previously referred to institutional care.

Since 1980, many conferences and seminars have drawn attention to residential service needs and provided technical assistance to providers. A report of a seminar held in 1980 serves to show that while some of the problems identified five years ago have been at least partially resolved, many of them continue to be concerns today. Progress, however, can be seen in the development of a uniform assessment process which is being funded by the Developmental Disabilities Planning Council. Another indicator of progress is the fact that community programs staff are now making visits to institutions to familiarize themselves with clients in preparation for transition to the community.

Perhaps one of the most interesting strengths of the New Mexico system today is that some of the problems experienced by persons with developmental disabilities in other states have been avoided in New Mexico. We did not deinstitutionalize at such a rapid rate that we replaced one institution for another -- the nursing home.

Strong, effective advocates in New Mexico have helped to lead the way towards appropriate services. Not only key advocates but leaders in state government and the private sector seem to agree on the critical need for a residential plan to guide the development of services.

V. SERVICE DELIVERY ISSUES

Five central issues regarding residential services were identified by HSRI in the initial phase of the project:

1. The future shape and magnitude of the residential system;
2. Funding sources and patterns;
3. Locus of decision making;
4. Future deinstitutionalization;
5. Needs of the multiply handicapped.

Each issue is made up of a series of questions. The discussion is drawn from the perspectives of state officials, providers, and consumers (or their advocates). Perspectives are based on interviews, reports, and other information and do not neccessarily represent the opinion of all persons who fall into these categories.

ISSUE 1: Future Shape and Magnitude of Residential Services

What should residential services look like? How can we assure that adults with developmental disabilities have meaningful day programs and opportunities for living in the least restrictive environment? Should there be a greater number of ICF/MR beds available to New Mexicans?

According to state officials, the "cap" on the number of ICF/MR beds makes it possible for the state to spend less on comparable residential services for persons with developmental disabilities. By placing some clients who are eligible for ICF/MR placement in group homes under the Medicaid waiver, the state derives more mileage for its Title XIX funding. The waiver program allows up to approximately $22,000 per client for residential and support services, whereas Medicaid costs under the ICF/MR program are at least 20% higher per year. According to some of those interviewed, the ICF/MR cap represents an important strength of the system in that it contains costs and redirects resources to comparable but less costly residences.

According to some providers, however, community capacity to serve more disabled clients is strained for the following reasons:

- A back-up system for crisis situations involving behavioral problems is not available on an emergency basis, nor are there adequate resources in the developmental disability or mental health system to provide appropriate counselling or other programs;
- Capital needed for facilities construction and improvements, and transportation are not considered the responsibility of the Department of Health and Environment in their legislative requests;
- Operating funds for programs are not at an adequate level to recruit and retain qualified staff and are insufficient to ensure client/staff ratios that are appropriate to the needs of persons with more severe handicapped.

In addition, some providers describe difficulties in locating residential programs due to local zoning restrictions that prohibit group homes in single-family areas.

State officials tend to agree that the location of residential services is an important consideration in the make-up of a system. For instance, location dictates a program's ability to hire and retain qualified staff, particularly in the ICF/MRs. Also certain administrative functions now provided centrally may be better carried-out on a regional basis -- for example, program monitoring and technical assistance. Further, regional program development may help to maximize scarce resources in rural areas. At present, the state is responding to a provider-initiated determination of the location of new services. Providers obtain local (private) or federal Section 202 funds from the Department of Housing and Urban Development for construction of new homes, then seek state support for their operation. Resource development is therefore driven by funding sources rather than systematic planning to achieve a service continuum.

According to many groups interviewed, there is no apparent incentive to move clients from groups homes to a less restrictive setting since funds are not necessarily available for the transition. The possibility of a continuum of living arrangements was further frustrated in 1983 with the passage of legislation which appropriated funds for group home operation only.

To assure that programs operate according to a standard of quality, the state relies on its licensing and monitoring capacity through HED. Providers expressed concern that licensing requirements are not consistent with principles of normalization and that family-like environments are not promoted through these regulations.

Providers have in many cases obtained an independent quality assurance review, either from the Commission on the Accreditation of Rehabilitation Facilities (CARF) or the Accreditation Council for Services for Mentally Retarded and other Developmental Disabilities (ACMR/DD). Whether these external reviews either complement or duplicate the state standard is unclear.

Consumers tended to view quality assurance issues differently and expressed an interest in being involved in reviewing and monitoring programs. The state should monitor programs using the "power of the purse" according to consumers. Consumers also describe frustration with a system that does very little to help the family keep their child at home. They noted that state monies go to support more expensive out-of-home models so that there is a disincentive for the family to retain responsibility for care. Placement of a child in specialized foster care, according to some parents makes families appear incompetent. Families need information on their role when the child moves into community programs, the relevance of various settings and services, and parent and client rights. Parents also expressed dissatisfaction with respite care in the state because of the inflexibility of the system. At present obtaining respite from state institutions involves considerable travel from home, and there is little respite service available on an as-needed basis close to home.

Other support services, namely work-related day programs for adults, were described by many as a major need. Such programs should include more than just token pay and should involve image-enhancing work opportunities for developmentally disabled persons. It is not known whether the shortage of such programs is the result of inadequate staff expertise, the lack of work incentives given the way services are financed, or external conditions such as the general economic and employment situation in specific communities.

In general there is a consensus that there is no incentive for placing clients in the least restrictive living arrangement and that there needs to be a means of determining the direction of growth of residential and day services. There is not agreement, however, about the role that the state should play in determining the type and extent of services received by an individual. This will be discussed further under the next issue.

ISSUE 2: Future Funding

How should residential services be financed? What type and amount of funding is needed? How do we keep costs to a minimum in a dwindling economy while providing an appropriate level of service?

From the state's perspective, New Mexico is facing tough decisions about priorities in response to the limited growth of state revenues. The cap on ICF/MR development is only an interim measure. There is also a need to:

1. develop a method for prioritizing service needs and assigning funding levels;
2. develop a mechanism for determining the appropriateness of residential placements based on level of functioning;
3. determine ways to support families -- both financially and in other ways -- in order to assist them to keep their children with developmental disabilities at home;
4. determine whether there are economic benefits to maintaining programs at a certain size (i.e., whether there is an economcy of scale in operating programs).

Regarding the first two items, it is anticipated that the Developmental Disablities Planning Council-funded project to develop uniform assessment criteria for adults will begin to address the need to categorize clients consistently statewide for placement purposes and for determining service needs.

With respect to the third item, the legislative appropriation for in-home care for medically-fragile children last year signified a step forward in developing family-based alternatives to institutions for a part of the population which is especially difficult to maintain in the home and community.

With respect to the adequacy of resources, many providers interviewed were concerned that the real needs of the population were not reflected in the 1985 legislative request by the Health and Environment Department which was only $100,000 for developmental disabilities. Providers estimate that $400,000 was needed for unit price equity alone. In addition the providers noted that state officials need to rethink their role in providing capital for community programs, that they need to leverage federal dollars through Medicaid for the maximum amount per client, and that they need to rid the system of income inequities associated with serving clients under the Medicaid waiver. With respect to the latter issue, the level of personal income allowable for clients under the waiver program is substantially lower than that allowed for clients living in ICF/MR facilities. Also, providers note that differences in compensation and staffing between waivered residences and ICF/MRs favor utilization of the latter. This discrepancy within community programs is expected to create low morale and other staffing problems in programs and across programs.

The question of how to finance services is viewed a little differently by consumers. From their perspective we must first know the true cost for both institutional and community based care, and that is not clear nor comprehensively reported at present. Then, if the client leaves the institution the money used for his services should go with him. In other words, services should be funded on the basis of individual needs for services and appropriated to individuals rather than programs. Consumers tend to agree with others that the state should assist in capital development for buildings, vehicles and so forth. To meet their needs, consumers, providers, and advocacy groups are increasingly turning directly to the legislature for financing services. This leads to the following issue.

ISSUE # 3: Locus of Decision-Making

Who is responsible for making decisions about unmet needs and how can we insure that steps are taken to follow through on decisions benefiting residential and support services?

In light of the changes in top-level decision makers in HED and the impact of federal initiatives on financing programs, it is no wonder that an air of uncertainty exists with regard to policy and long-term direction of the developmental disabilities service system.

Providers expressed concern that they do not have an opportunity to make input into policy changes and priorities. In order to convey their needs to budget planners, providers and consumers have turned increasingly to the legislature and to the federal government. Further it appears to providers that the institutions continue to get more than their fair share of the funding for developmental disabilities services, and that they lack adequate "clout" in state government to obtain needed resources.

Parents of persons with developmental disabilities would like to see greater local decision-making power regarding services in their community. Many parents feel that they are able to decide what is best for their child, and perhaps feel threatened by state government and legal intervention. Although it is acknowledged that some persons with developmental disabilities need advocates, parents are still the primary decision makers in this state, even for adults. Decisions about residential placement are of particular concern to parents.

From the state perspective, the lack of a planning directive has led to a provider-driven system. Providers determine the location and types of services, seek their own appropriations, and have found a means of circumventing the state's efforts to contain expansion of the Medicaid program for ICF/MR-eligibile clients.

A common concern of state officials, providers, and consumers is how to make residential services planning more effective. In order for the plan to be effective the cooperation of numerous agencies is needed. Concern that previous studies and reports contain recommendations that are "gathering dust on the shelf" gives weight to the scepticism about the usefulness of planning. State officials are also concerned about the need for external consultants to facilitate residential planning and desire ways of making the process self-sufficient in the future.

ISSUE # 4: Future of Deinstitutionalization

Should we find an alternative use for Fort Stanton Hospital and Training School or does it have a place in the residential service system in the future? How can we provide stability for clients placed in the community which is comparable to the institution?

Perhaps the most controversial issue in residential services at present is the question of whether to close Fort Stanton. The announcement to close Fort Stanton over two years beginning in 1983 was generally felt to be unplanned and poorly timed in terms of the community program's ability to fill the gap. The shortage in community residential beds and a gap in crisis support for clients, especially those with severe behavior problems, worked to defeat the closure proposal. Also, considerable concern was raised by parents about removal of Fort Stanton from the service continuum since some felt it represented an important resource for persons who do best in a rural environment where they can be assured that adequate staff are available.

The anxiety about community programs that may be "here today and gone tommorow" has been reinforced by recent administrative initiatives in HED to cut community programs and the growth in waiting lists for community placements. In addition, a number of clients have "failed" in community program settings because of an inability to cope with their needs. If the institution were not there, argue some families and providers, there would no back-up resource for such clients. Further reluctance to close the institution stems from differences in funding levels between the two settings, indicating that adequate resources may not be available to provide comparable care.

Providers share many of the same concerns, and while they generally support deinstitutionalization, they feel that adequate financing of community services must occur at the same time. Under the original Medicaid waiver submitted by the state, Fort Stanton's funds could be reallocated to pay for services for most Fort Stanton residents if these persons made the transition to the community. This would mean the eventual closure of a Fort Stanton bed for each new bed opened in the community, or would require the support of Fort Stanton beds with state general funds. From the state perspective this can only be accomplished if the following is determined:

1. Whether it is more feasible from a program point of view to close the institution all at once or phase it down over time.
2. Whether adequate community resources are in place for all clients who are slated for community placement.
3. Whether an alternative use for this state facility has been established which can meet the economic needs of surrounding communities that have become dependent on the facility for income.

With court orders mandating that certain clients at Fort Stanton be placed in less restrictive settings, and with long waiting lists for placement, it is clear to all concerned that a significant movement of clients is indicated and that additional community openings are needed. Opinions about the future role of the institution in residential services vary greatly -- from closure, to reduction, to use for special sub-populations (e.g., bahavior problems, etc.), to maintenance at its existing level.

There is some concern that uncertainity about the future of Fort Stanton places residents at-risk. Threatened with the possible loss of jobs, staff are placed in the unenviable position of having to defend the need for continuation of the program by emphasizing the level of disability of the residents. Some fear that this position affects the staffs perception of the residents and ultimately their expectations of client functioning. This attitudinal problem plus potential negative impact on staff morale are important reasons for the development of a binding plan to govern the future of Fort Stanton.

ISSUE # 5: Services for Persons with Multiple Handicaps

How can we meet the needs of the persons with developmental disabilities who have a second disability such as deafness, a mental health problem or or substance abuse, or who have some involvement with the criminal system?

Often described as the persons who "fall through the cracks" in the current service delivery system, the number of persons who have special needs in addition to those created by their developmental disability is unknown. These are persons who are often passed from one agency to another, not "fitting" into any one program. From the state's perspective the developmentally disabled person with a mental health problem has been at least partially addressed by the outcomes of the Montano v. Goldstein suit. Community resources are not available due to the lack of staff expertise in community programs, and the possibility of deploying institutional staff with expertise to provide training is being considered.

Training as well as hiring staff qualified to meet the needs of persons with multiple handicaps is a financing problem from the provider's perspective. Furthermore, the number of different target groups suggests a possible need for provider specialization in such areas as services to elderly developmentally disabled persons. Institutional staff can provide some training and technical assistance but the need extends beyond their capability and some of those interviewed recommended the development of specially-designed and funded programs within agencies, ongoing training programs, and better-paid staff. The manpower study conducted by Gollay and Associates (1983) reinforces these conclusions.

Conclusion

In conclusion it is worth noting that the political and economic climate in New Mexico has a significant role in the future development of residential and support services. In recent years a consensus has emerged that the persons with developmental disabilities should fall in the "safety net" of government assistance. The extent to which the family should share in the responsibility for financing, at least to the degree they are able, is not as clear.

Some legislators feel that persons with developmental disabilities have had their "fair share" of resources, while others are still convinced that the system needs improvement and expansion. To complicate matters, New Mexico is facing the impact of dwindling oil and gas revenues, a major source of revenue for the state. The likelihood of additional resources to fund new services is uncertain and probably will remain so for the next few years.

In light of this situation, New Mexicans must make the best use of existing resources to meet the demand for residential services while developing an accurate and rational projection of funds needed for new programs.

VI. NEW MEXICO IN PERSPECTIVE: DESIGN ISSUES AND COMPARATIVE DATA

The purpose of this section is to review how the state of New Mexico stands in relation to what other states are doing to provide community-based services for their citizens with developmental disabilities. To achieve this end, secondary data from completed national surveys is presented for family support services, and community residential and day programs. In addition, data concerning the relative allocation of funds between community and institutional settings is also presented.

A. Family Support Systems

1. Program Goals

A family support system is defined as a statewide initiative to provide systematic support to families who provide home care to persons with developmental disabilities that is funded and monitored through the administrative auspices of the state. Underlying such initiatives are three fundamental goals: 1) to strengthen the family's capacity for providing superior home care, 2) to prevent undue out-of-home placements, and 3)to provide families with the resources they need to have their member with disabilities return home from an out-of-home placement.

Family support systems designed to achieve these ends ought to be guided by three basic concerns:

- Family Empowerment. Family support systems should be "family driven." That is, families should have a say over the substance, administration, and planning of services;
- Matching Appropriate Resources with Service Needs. Services should be designed to offer families appropriate types and levels of assistance. This implies that an array of suppportive services should be available and that services should be provided to families in a timely fashion when needed; and

- Efficient Allocation of Resources. Present economic realities challenge policy makers to determine fair and efficient means for allocating limited resources. Should service systems accommodate all caregiving families at the risk of diluting the services they receive? Or should only families deemed to be "at risk" be served? At present, it appears that the latter course has been chosen, but disagreement exists with regard to the best means for identifying families who are in greatest need of assistance.

2. National Perspective

Recent survey results show that all states but Oklahoma indicate the presence of some type of family support program (Agosta, Jennings & Bradley, 1985). These programs, however, vary considerably along two key dimensions: means of administration and overall extensiveness.

a. Means of Administration. Existing family support systems can be divided into three administrative categories:

- Cash assistance programs that provide families with money to offset the costs of habilitative services or materials. Families either receive a periodic stipend or subsidy to pay for future expenses or are reimbursed for costs of care incurred;
- Supportive programs that provide free in-kind services (e.g., parent training) and/or habilitative materials (e.g., personal or environmental prosthetics),
- Combination programs that offer both cash and in kind support.

Figure 15 displays the 49 states that administer family support programs according to which administrative category best exemplifies each state's family support system. Review of this figure shows that nine states provide cash assistance primarily, 33 provide in-kind services, and seven provide both. New Mexico appears in the supportive services only category.

b. Overall comprehensiveness Though nearly all states administer a family support program, few offer services that are

Figure 15: States Offering Family Support Services by Primary Administrative Category

Cash Assistance Programs

1. Connecticut
2. Idaho
3. Illinois*
4. Indiana
5. Louisiana
6. Minnesota
7. Nevada
8. North Dakota
9. South Carolina

Supportive Service Programs

1. Alabama
2. Alaska
3. Arizona
4. Arkansas
5. California
6. Colorado
7. Delaware
8. Georgia
9. Hawaii
10. Iowa*
11. Kansas
12. Kentucky
13. Maine
14. Massachusetts
15. Mississippi
16. Missouri
17. New Hampshire
18. New Jersey
19. New Mexico
20. New York
21. North Carolina
22. Ohio
23. Oregon
24. Pennsylvania
25. South Dakota
26. Tennessee
27. Texas
28. Utah
29. Vermont
30. Virginia
31. Washington
32. West Virginia
33. Wyoming

Combination Programs

1. Florida
2. Maryland
3. Michigan
4. Montana
5. Nebraska
6. Rhode Island
7. Wisconsin

* The Illinois state legislature has ratified a bill to permit operation of a cash assistance program but has not yet appropriated funding for the approved program. The state's Developmental Disabilities Council, however, has recently funded a $45,000 pilot support services program.

** The Iowa State Developmental Disabilities Council had funded a cash assistance program since 1981 but terminated funding on 9/30/84. The state does provide certain supportive services and is developing means for offering additional services through a private Community Living Foundation.

extensive in terms of the array of offered services and in the number of families served. Figure 16 displays an array of services that should be available to families throughout any given service area. Review of available information on existing service systems reveals that few states have developed service systems that encompass most, if not all, of these needed services. Many states recognize the importance of supporting family efforts but offer only a few services such as case management, limited respite care, or informational services.

Second, information suggests that the great majority of persons with developmental disabilities live at home with their families. Yet, existing family support programs serve relatively few families. Numbers served per state range from 35,000 in California to 15 families in Connecticut and South Carolina. Most family suppport programs that offer an extensive service array serve between 150-200 families with California, Pennsylvania (11,548), Michigan (up to 2,400), New Jersey (850), Montana, (850), and Washington (800) leading the way.

3. Family Support in New Mexico

New Mexico has initiated a modest system of supportive services for families who provide home care to persons with developmental disabilities. Figure 17 displays the relative availability of five support services according to the age of family member with developmental disabilities.

In addition to these efforts, the New Mexico Developmental Disabilities Planning Council recently allocated funds to develop a support system for parents. As a result, the Parent Involvement Center and the Taos Association for Retarded

Figure 16: Model Array of Family Resource Systems and Support Services for Persons with Disabilities and Their Families

(Source: Loop & Hitzing, 1980)

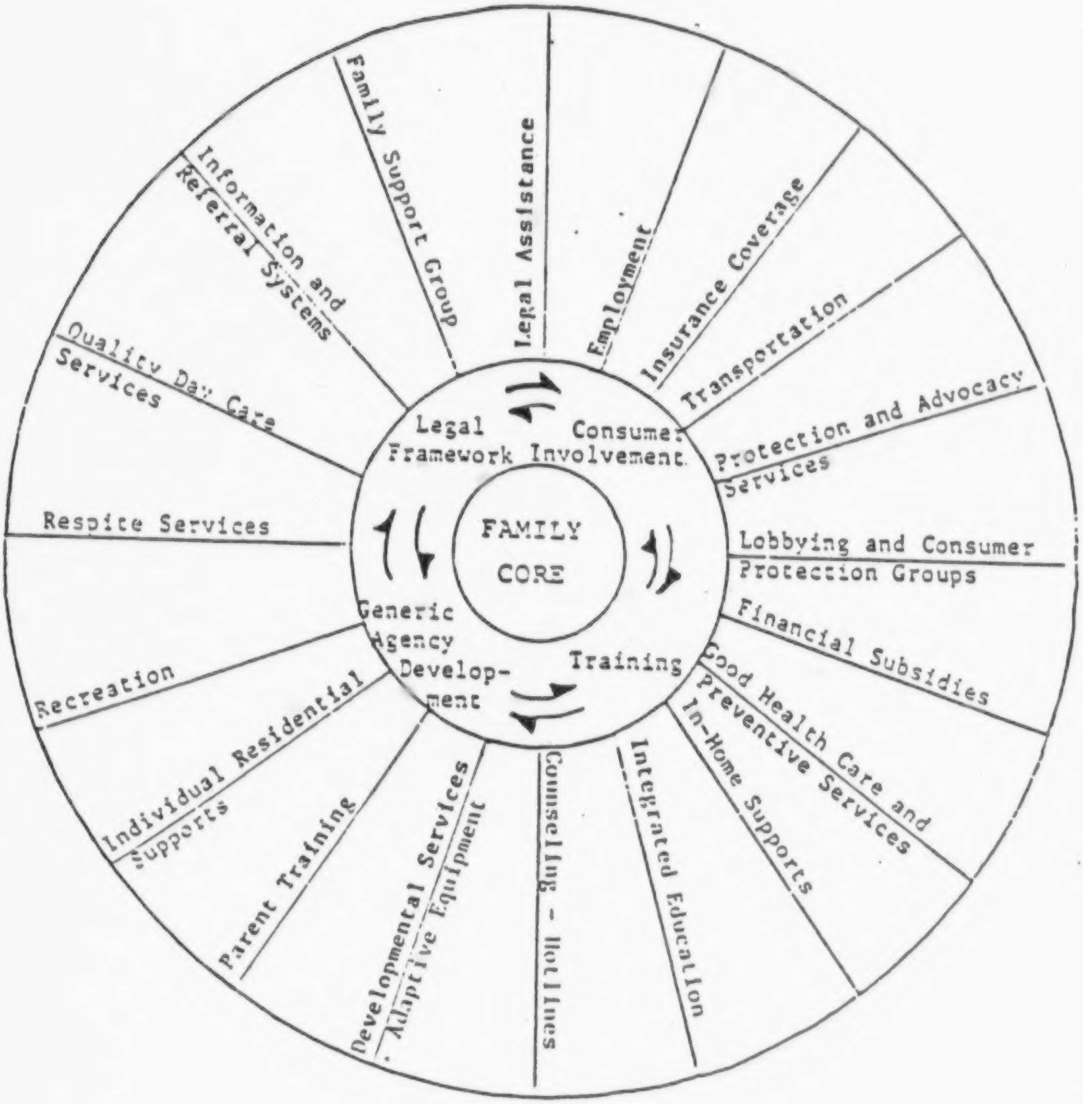

FAMILY CORE
Legal Framework
Consumer Involvement
Training
Generic Agency Development
Legal Assistance
Employment
Insurance Coverage
Transportation
Protection and Advocacy Services
Lobbying and Consumer Protection Groups
Financial Subsidies
Good Health Care and Preventive Services
In-Home Supports
Integrated Education
Counseling - Hot Lines
Developmental Services Adaptive Equipment
Parent Training
Individual Residential Supports
Recreation
Respite Services
Quality Day Care Services
Information and Referral Systems
Family Support Group

Figure 17: FAMILY SUPPORT SERVICES IN NEW MEXICO

STATE-SUPPORTED PROGRAMS	PRESCHOOL	SCHOOL-AGE	ADULT
Respite	Available to approximately 150 individuals for a maximum of two weeks per year		
Family Counselling	Available to less than 5% of DD individuals	Extent unknown	Available to less than 5% of DD individuals
Family Training	Available to less than 25%	Extent unknown	Available to less than 5% of DD individuals
In-home Care: Homemaker Personal Care Nursing	The Human Services Department currently has a waiting list for persons eligible for these services and estimates that less than 100 DD persons are currently in their program; it is also reported that the current amount and duration of services allowed under this program is usually not sufficient to meet the needs of DD persons.		
Case Management	Available to approximately 10% of DD individuals		

Information obtained from The Early Years: A Plan for New Mexico's Developmentally Disabled Children; DDPC, 1983 per conversation with Elinor Gollay, Director of Administrative Services Division, HSD; CO-OP Data System, HED; and Review and Recommendations on Manpower Needs of Community Programs for Developmentally Disabled in New Mexico, by Gollay and Associates, 1983.

Citizens initiated the "Parent Support Network." This project employs a core staff and established support teams consisting of parents and professionals in the state's seven service districts.

Each team is expected to undertake activities designed to provide support and information to families who provide home care by coordinating with existing agencies, developing novel strategies as needed, and obtaining additional technical assistance when necssary. To enhance the program's effectiveness, team members receive training regarding means for providing support and information to families, and each team receives stipends for purchasing training materials, books, rental space to hold meetings or other items essential for establishing a support and information network in their service areas.

The above initiatives represent a strong beginning. Among their primary strengths are their reliance on building partnerships between professionals and parents, their emphasis on locally referenced strategies, and their responsiveness to the unique needs of individual families.

The family support program in New Mexico, however, as in numerous other states, is far from comprehensive. Interviews conducted in New Mexico, highlighted in the previous section (See IV B), also indicate that family supports, such as respite care, are inadequate and often difficult to access. Figure 18 displays a sample of 22 states with the most advanced family support networks, while Figure 19 shows what services are made available through these programs. In comparison to these states, these figures suggest that much can still be done in New Mexico to develop a comprehensive system of family support.

Figure 18: Eight Cash Assistance Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
Connecticut	1981	Cash Program	$2,000 per year	15	$23,106	developmental disabilities	sliding scale based on income and family size; no other public assistance received	at risk of out-of-home placement or returning from such placement
Idaho	1981	Cash Program	$250.00 per month ($3,000 per year)	138	$47,000	developmental disabilities; under age 21		priority to those at risk out-of-home placement or returning from such placement
Indiana	1982	Cash Program	Determined by casemanger, maximum of $500 per month for respite	191	$185,000 (FY 1985)	developmental disabilities		priority to those at risk of out-of-home placement
Louisiana	1983	Cash Program	$375.00 per month ($4,500 per year)	25	$112,500	mental retardation		
Minnesota	1975	Cash Program	$250.00 per month (3,000 per year)	190	$525,000	primary diagnosis of mental retardation; under age 18; priority to severest disability	, priority to greatest resource needs	
Nevada	1981	Cash Program	$286.00 per month ($3,432 per year)	67	$110,000	profound mental retardation	insufficient income to cover costs of care; sliding scale based on family income & size	
North Dakota	1981	Cash Program	$15/week for basic care; $35/week for services/ treatment ($2,600 per year)	200	$200,000 (3 year pilot)	developmental disabilities; under age 21		
South Carolina	1974	Cash Program	150.00 per month. ($1,800 per year)	15	$23,000	mental retardation	insufficient income to cover costs of care	

-CONTINUED-

Figure 18: Seven Support Services Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
California	1982	Support Services	varies by individual but no set limit	35,000 (all ages)	$5,100,000 (for persons under 18 years)	developmental disabilities		
New Jersey	1980	Support Services	No limit on intervention services but only 30 days respite/year	850	$967,187	mental retardation	means income eligibility standard	
Ohio	1983	Support Services	$2,500 per year	Program initiated 4-1-84	$700,000	developmental disabilities		
Oregon	1983	Support Services	No set limit	about 1,000	$3,100,000	developmental disabilities; under age 6		
Pennsylvania	1972	Support Services	No set limit	11,548	$3,437,273	mental retardation		
Vermont	1973	Support Services	$990.00 per year	260	$381,279	mental retardation		
Washington	1977	Support Services	$750.00 per year	800	$2,154,000	developmental disabilities		

-CONTINUED-

Figure 18: Seven Combination Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
Florida	1978	Combination Program	Based on need; no maximum	8,227 (210 in Cash Program)	$21,000,000 (1,200,000 for Cash Program)	developmental disabilities		at risk of out-of-home placement if services not received
Maryland	1984	Combination Program	No set limit; based on need within reason	103	$197,000	developmental disabilities under age 22		at risk of an out-of-home placement
Michigan	1984	Cash Program	$225.00 per month ($2,700 per year)	Estimated at 2,000	$5,700,000 (est. FY 1985)	severe mental or multiple impairment, autism; under age 18	family taxable income for year preceding application cannot exceed $60,000	
	1983	Support Services	No set limit; limited by budget	355	$495,000	developmental disabilities		
Montana	1975	Combination Program	$1,335 per year	600	$1,125,000	No set priority but preference to young and severe disabilities		
Nebraska	1982	Combination Program	$300.00 per month averaged over one year	115	$200,000	developmental disabilities	insufficient income to cover costs of care	
Rhode Island	1981	Combination Program	$60/week for basic care, $15/week for training ($3,900/year)	65	$256,000	mental retardation; mental illness; chronic impairments		resident of state residential facility for 90 days to receive a cash subsidy
Wisconsin	1984	Combination but varies across the state	$3,000 per year	197	$125,000	severe disabilities; children	no access to sufficient funds to cover costs of care	at risk of an out-of-home placement or returning home from such placement

Figure 19: Permissible Services in 22 Family Support Programs

SERVICES	STATES																						TOTAL
	CA	CT	FL	ID	IN	LA	MD	MI	MN	MT	NB	NV	NJ	ND	OH	OR	PA	RI	SC	VT	WA	WI	
Adaptive Equipment	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x			x	x	x	x	x	20
Educational or Therapeutic Services for disabled person (examples include physical, speech or vocational therapy, behavior management)	x	x	x	x		x	x	x	x	x			x	x		x	x	x	x	x	x		17
Transportation	x	x	x	x	x		x	x	x	x	x	x		x		x			x		x	x	16
Medical or Dental Services	x	x	x	x	x	x	x	x	x		x			x				x	x			x	14
Housing Modifications	x		x	x		x	x	x	x		x			x	x		x	x	x			x	14
Special Clothing	x	x	x	x				x	x			x		x						x		x	10
Diet or Nutrition Services			x	x		x	x	x	x			x		x	x							x	10
Diagnosis and Assessment	x		x	x				x	x	x	x			x								x	9
Medications		x	x			x	x	x	x		x								x				8
Home Health Care				x		x	x	x			x		x	x									7
Personal or Attendant Care	x					x	x	x			x												5
Recreational Services			x	x										x			x					x	5
Information and Referral										x						x							2
Temporary Respite or Relief	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	21
Family Training or Counseling	x	x	x	x		x	x		x	x	x			x	x	x	x	x				x	15
Homemaker	x						x		x		x		x				x	x					7
Chore Services	x						x				x												3
Housekeeping	x						x				x												3
Room/Board for Family (for traveling related to provision of care)			x								x												2
TOTAL:	13	8	13	12	4	10	14	12	12	7	14	5	5	12	5	4	6	7	7	4	4	10	
Provisions for permitting unique services not available elsewhere	x	x	x	x	x		x	x		x							x		x			x	11

B. Community Residential Alternatives

1. Program Goals

Residential services for persons with developmental disabilities should be guided by the following set of principles and assumptions:

- individualization -- services should be tailored to meet the unique needs and circumstances of persons with disabilities. Each resident should participate in a personalized planning process where habilitaive goals, objectives and methods are specified;
- integration -- residential options must be oraganized and located in ways that maximize the ability of individuals to interact with others in the community. Residential settings should house no more than six persons and be designed so that they could be made less restrictive without needing to move the client to an alternative setting (e.g., supervised apartments);
- programming away from the home -- persons with developmental disabilities should receive daytime instruction away from the home. Further, to the extent feasible, such instruction should emphasize vocational objectives within integrated settings (e.g., sheltered enclaves, affirmative industry, supported employment);
- family involvement -- to the extent feasible, the family of the person with disabilities should be involved in planning individual habilitation service plans; and
- advocacy and oversight -- residential services can not be developed in a vacuum. To ensure the well-being of persons with disabilities living in the community, advocacy systems must be available to represent the interests of clients and administrative structures must be in place to guarantee that services are implemented according to individual plans.

2. National Perspective

Residential services for persons with developmental disabilities have been in a period of substantial flux for nearly two decades. During this period statistics show that the population of traditional state institutions for persons with mental retardation decreased from a high of 194,650 in 1967 to just over 125,000 in 1981 and the number of persons receiving community services increased from 26,000 in 1967 to an estimated 90,000 today (Lakin, Bruininks, Doth, Hill & Hauber, 1982).

Describing the array of community residential alternatives around the country is a difficult task. Part of the problem is due to the inconsistency from state to state regarding the means by which services are described. To overcome this problem, staff at the University of Minnesota created a uniform taxonomy involving six residential categories. Subsequently, they conducted two national surveys of residential facilities for persons with mental retardation/developmental disabilities (see Bruininks, Hauber & Kudla, 1979; Bruininks, Hill & Thorsheim, 1982; Hauber, Bruininks, Hill, Lakin, Scheerenberger & White, 1985).

The categories used during these surveys included:

- foster homes: comprises existing families in their own homes along with one or more handicapped residents who are not family residents;
- group residences: includes facilities of varying size and levels of supervision;
- semi-independent living programs: programs residents have their own living quarters with staff living nearby;
- boarding homes: programs that provide sleeping rooms, meals, and often housekeeping but no training or formal supervision;
- personal care homes: these are small, family-run homes that sometimes resemble foster homes but are often operated in a convalescent or rest home tradition;
- supported independent living: programs where persons have their own homes or apartments, are responsible for their own day-to-day activities, and are visited by staff periodically.

Figure 20 displays information collected during the 1977 and 1982 surveys according to the residential cateogries noted above. In general, previous trends in residential services were largely maintained between 1977-1982. The period, however, also produced some changes of note:

- Residents of the service system in 1982 were older and slightly more severely handicapped that those who were being served five years earlier;
- Public faclities which continue to phase down at a fairly constant rate of 6,000 residents per year are being replaced primarily by smaller community programs that serve severely/profoundly handicapped individuals;
- The number of residents in large private facilities did not increase between 1977 and 1982, but the rate of growth slowed considerably and the population shifted significantly in the direction of older, more severely retarded and functionally impaired residents.
- The number of severely/profoundly retarded persons in family care and small group care reinforces the belief that they can be served satisfactorily outside of institutions.

3. Community Residential Options in New Mexico

The numbers of persons with developmental disabilities remaining in public and private institutions varies dramatically among states. Figure 21 displays rates of institutionalization in public facilities per 100,000 persons by size of facility. Review of this figure reveals that:

- Some states (e.g., Michigan, Montana, and Vermont) seem on the way toward phasing out institutional models, while other states (e.g., North Dakota, Oklahoma, Wyoming, and Texas) have disproportionate numbers of persons living in facilities for 16 or more persons.
- New Mexico has a lower rate of placement for all out-of-home residential alternatives than all but six states.
- New Mexico favors residential alternatives designed for 16 or more persons;

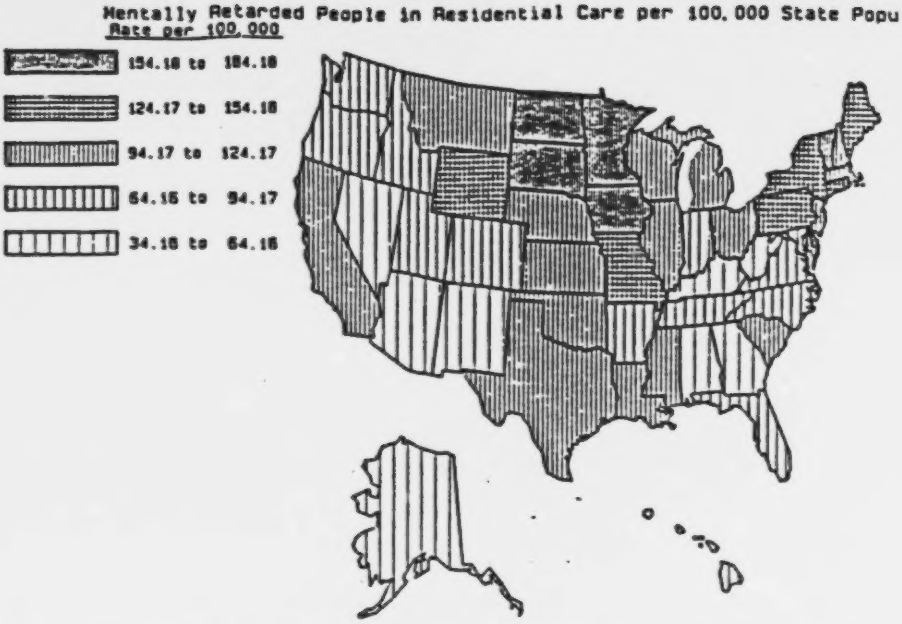
Figure 20

Characteristics of Residential Facilities for Mentally Retarded People in the United States: June 30, 1982

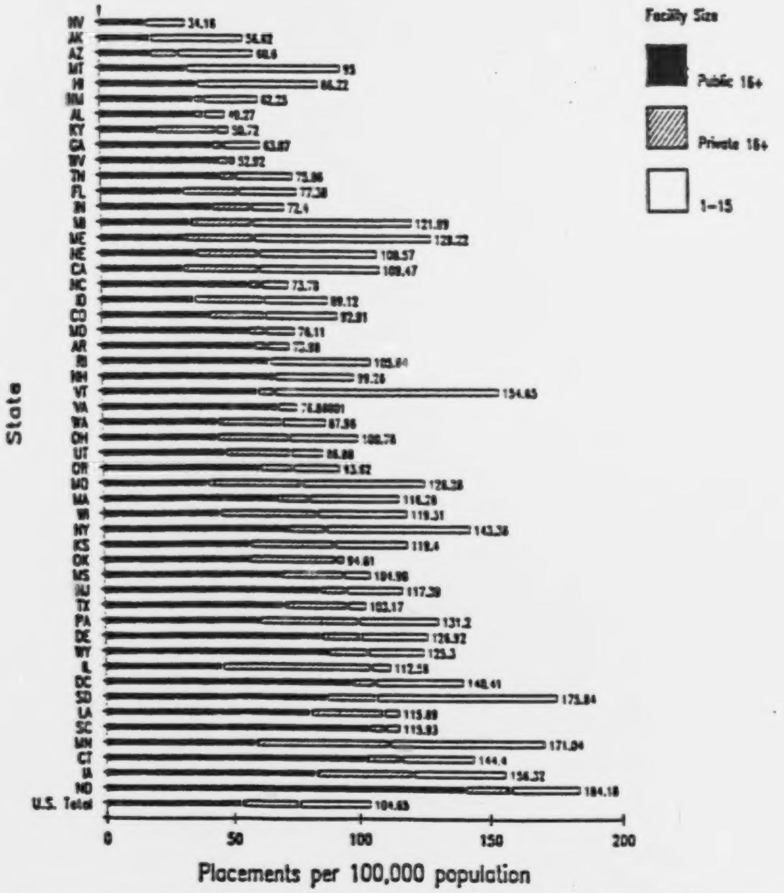
Characteristics	Spec. Foster 1977	Spec. Foster 1982	Group res. 1-15 1977	Group res. 1-15 1982	Group res. Private 16+ 1977	Group res. Private 16+ 1982	Group res. Public 16+ 1977	Group res. Public 16+ 1982	Semi-Independent 1977	Semi-Independent 1982	Board & Room 1977	Board & Room 1982	Personal Care 1977	Personal Care 1982	Spec. Nursing 1977	Spec. Nursing 1982	Total 1977	Total 1982
Facility characteristics																		
Number of facilities	5,332	6,587	3,225	6,414	850	886	362	359	236	304	210	185	661	583	249	303	11,025	15,633
Number of residents	15,435	18,252	24,331	43,500	43,336	46,060	167,212	134,943	2,356	3,156	2,955	2,550	9,105	7,956	21,103	24,521	285,913	281,042
M	2.7	2.8	7.0	6.8	44.0	52.0	429.9	365.7	8.9	10.3	8.3	13.8	7.4	13.6	45.9	81.1	22.7	18.0
SD	1.8	1.9	3.2	3.2	50.2	55.7	525.8	383.9	8.6	8.8	11.0	20.3	9.7	19.8	56.2	61.0	123.4	83.0
Number of MR residents	14,418	17,147	22,449	42,018	36,998	40,347	154,656	122,971	1,993	2,870	1,665	1,264	4,141	4,070	11,275	12,982	247,796	243,669
Operator																		
Private/proprietary	100.0%	100.0%	40.0%	27.1%	50.7%	50.2%	.0	.0	15.0%	13.4%	93.5%	94.6%	90.9%	90.4%	76.5%	70.6%	72.4%	62.2%
Non-profit	.0	.0	48.2%	63.6%	49.3%	49.8%	.0	.0	75.8%	80.4%	5.5%	4.3%	4.5%	4.8%	18.0%	23.1%	20.2%	31.2%
Public	.0	.0	11.8%	9.2%	.0	.0	100.0%	100.0%	9.2%	6.2%	1.0%	1.1%	4.6%	4.8%	5.5%	6.3%	7.3%	6.6%
Avg. per diem per resident	$9.41	$16.15	$16.52	$30.31	$22.70	$45.15	$43.53	$85.84	$16.20	$27.40	$9.60	$15.97	$12.60	$17.06	$25.92	$49.81	$34.23	$61.80
Movement																		
New admissions	22.4%	19.0%	37.2%	25.7%	20.3%	15.6%	6.7%	5.9%	54.2%	31.9%	30.0%	12.7%	19.0%	14.7%	23.0%	14.4%	13.3%	12.0%
Readmissions	2.3%	.9%	2.0%	1.2%	1.4%	1.3%	2.1%	1.9%	1.1%	1.0%	3.0%	.9%	3.0%	2.3%	4.7%	2.7%	2.2%	1.7%
Releases	7.0%	7.9%	10.5%	14.0%	13.7%	12.0%	9.2%	11.4%	24.0%	10.5%	16.4%	13.0%	10.9%	8.5%	15.5%	8.0%	11.1%	11.5%
Deaths	.9%	.9%	.6%	.5%	.8%	.8%	1.7%	1.5%	.4%	.3%	.9%	.9%	1.1%	.8%	3.1%	2.7%	1.5%	1.2%
Est. move due to close	8.7%	.8%	6.2%	5.0%	2.4%	2.5%	.4%	4.5%	9.7%	9.4%	7.4%	6.0%	6.7%	5.7%	2.5%	2.6%	2.0%	2.7%
Est. net 12 month change	8.2%	2.3%	14.5%	6.6%	4.5%	1.7%	-3.6%	-5.6%	20.6%	4.9%	8.3%	-7.1%	4.6%	2.0%	6.6%	4.3%	.8%	-1.0%
Opened within 4 1/2 years	51.2%	46.6%	60.5%	40.0%	35.6%	19.7%	17.3%	8.0%	86.1%	62.5%	30.0%	21.4%	37.2%	27.4%	41.7%	23.3%	53.0%	40.6%
Resident characteristics																		
Age																		
< 22	39.6%	37.4%	28.6%	19.8%	44.4%	32.0%	35.0%	22.0%	17.7%	7.7%	10.1%	5.9%	14.7%	10.2%	52.9%	38.2%	35.8%	24.8%
22-39	24.7%	32.0%	47.9%	53.3%	36.7%	41.0%	41.3%	50.2%	61.3%	65.4%	33.0%	38.3%	28.0%	31.6%	22.3%	33.6%	39.3%	47.0%
40-62	26.7%	23.1%	21.2%	23.8%	16.3%	22.1%	19.2%	22.9%	20.3%	25.5%	42.0%	40.5%	43.9%	41.1%	18.3%	21.8%	19.9%	23.3%
63+	9.1%	4.9%	2.2%	3.0%	2.6%	4.1%	3.7%	5.0%	.7%	1.5%	14.2%	15.3%	13.4%	17.1%	6.4%	6.4%	4.1%	4.8%
Level of retardation																		
Borderline/mild	28.0%	25.9%	34.4%	29.3%	29.6%	26.8%	9.3%	7.0%	66.1%	61.8%	49.5%	47.1%	30.6%	32.2%	12.0%	9.2%	16.9%	16.8%
Moderate	37.7%	37.7%	41.7%	37.9%	34.9%	29.9%	16.0%	12.9%	31.1%	32.5%	40.8%	33.8%	40.4%	39.8%	21.0%	16.2%	23.4%	22.8%
Severe	26.5%	26.0%	19.5%	23.2%	23.4%	24.0%	27.9%	24.3%	2.7%	5.3%	7.1%	18.0%	18.0%	20.6%	36.9%	26.2%	26.2%	24.0%
Profound	7.8%	10.4%	4.4%	9.5%	12.2%	19.3%	46.9%	55.8%	.1%	.4%	2.6%	1.7%	11.1%	8.4%	30.0%	48.5%	33.5%	36.5%
Nonambulatory	7.0%	9.3%	3.5%	5.3%	8.4%	14.4%	23.3%	25.5%	6.0%	3.7%	1.0%	2.7%	6.6%	5.4%	49.3%	48.3%	18.9%	19.5%
Cannot talk	18.6%	24.9%	11.2%	17.4%	19.7%	24.1%	43.5%	49.1%	3.3%	3.7%	6.5%	4.8%	13.0%	16.1%	60.5%	54.0%	34.7%	36.7%
Not toilet trained	8.0%	13.1%	4.2%	6.7%	11.6%	16.1%	34.1%	30.0%	.0%	.1%	1.0%	3.9%	6.0%	6.5%	45.2%	40.0%	26.1%	26.7%

FIGURE 21

Mentally Retarded People in Residential Care per 100,000 State Population



Mentally Retarded People in Residential Care per 100,000 State Population



Source: Lakin, K.C., Hill, B.K., & Bruininks, R.H. (Eds.) (1985). An Analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) Program. Minneapolis: University of Minnesota, Department of Educational Psychology.

- Given a commitment to establish community residential services for persons with developmental disabilities, New Mexico is in a better position that many other states but much still needs to be done.

This final observation is substantiated by review of information specific to New Mexico. Historical trends regarding residential services for persons with developmental disabilities persons in New Mexico reflects a picture of sporadic growth in community-based living arrangements and a limited continuum of services. Most recently, expansion and redistribution of state and federal funds has allowed for nearly 100 additional placements in community residential services, representing a 30% growth in a 12 month period. This opportunity for expansion was made possible by a legislative appropriation of $673,00 in 1983 and the recent approval of a Medicaid waiver.

Efforts to meet the needs of new, as well as, current clients have met with numerous difficulties in the community-based provider system including:

- difficulties with implementing the Title XIX Waiver Program (Burwell, 1985);
- zoning controversies;
- delays in obtaining funding for housing projects under the U.S. Department of Housing and Urban Development (Section 202 loan program);
- difficulities experienced by community based providers to fund current levels of operation;
- insufficient numbers of qualified persons to provide direct care within residential settings; and
- high levels of staff "burnout" and turnover.

Although New Mexico has taken great strides away from institutional models and toward a continuum of community residential alternatives, numerous barriers must still be overcome. In essence, the present residential system is characterized by a lack of appropriate alternatives in least restrictive settings.

C. Day Services

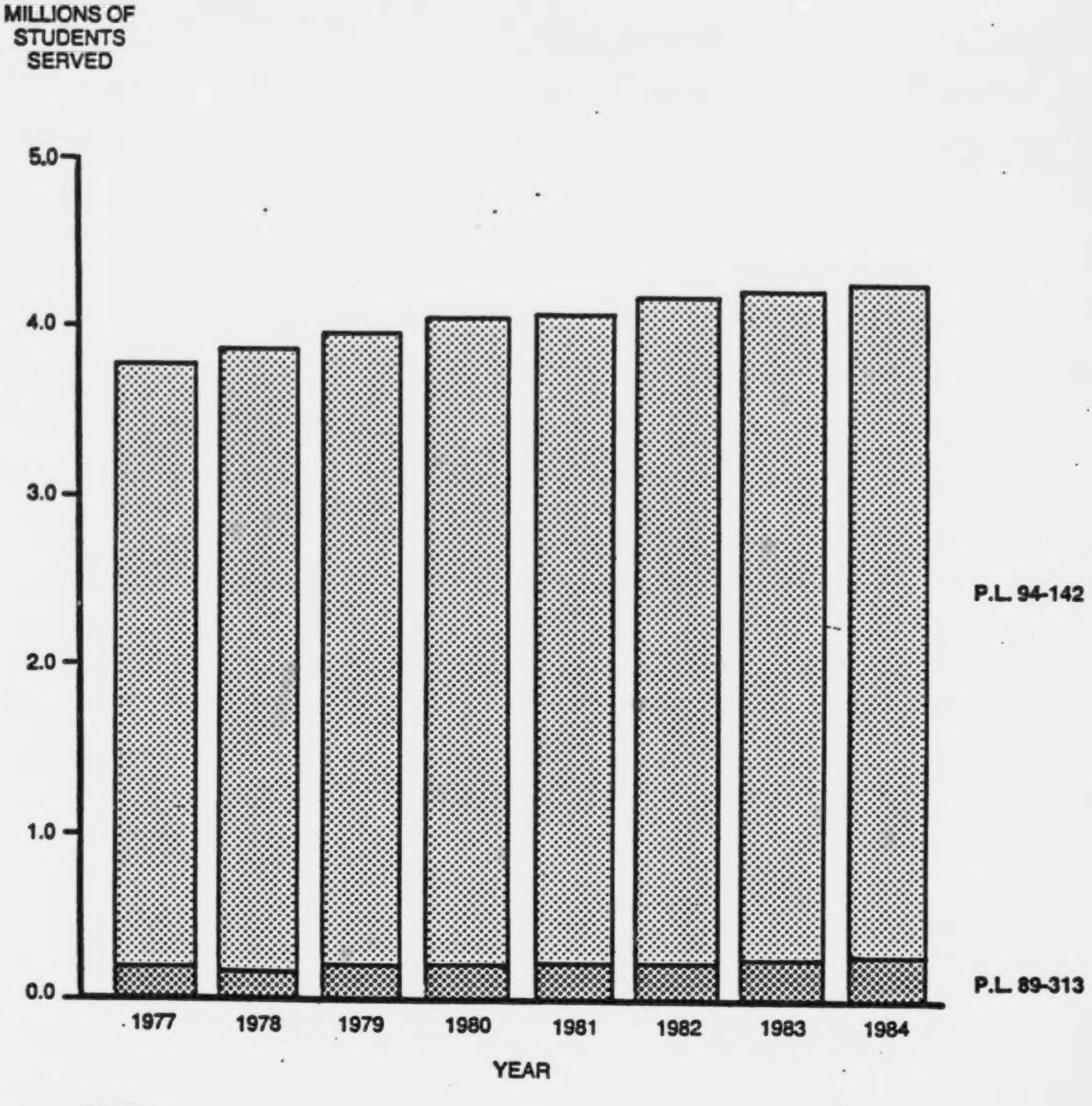
Like family support and residential alternatives, day services are an essential component to a community care system. At the least, these services provide habilitative training related to developmental, academic, or vocational skills, but also can offer instruction in community life skills (e.g., travel training, banking) or specialized therapies (e.g., speech, physical). Systems of day service must be flexible enough to match the varying needs of persons with developmental disabilities throughout their life. As a result, these systems can be divided into three components: early childhood services (0-5 years), public school services (5-21 years) and vocational services (21 years and above).

1. Early Childhood Services

Across the country, the implementation of the Education of the Handicapped Act, as amended by P.L. 94-142, spurred signifcant increases in the nature and extent of educational services for young children with disabilities. The U.S. Department of Education (DOE) notes that states continue to report increases in the number of preschool children with disabilities served, especially those aged 3-5. Figure 22 shows the number and percent change of preschool children with disabilities served from 1976-77 to 1983-84 and shows that during that period there was a steady increase in those served.

Figure 22: **Number of Children Served Under P.L. 89-313 and P.L. 94-142 From 1976-77 Through 1983-84 in the U.S. and Insular Areas** [1]

Source: Division of Education Services Special Education Programs, 1985



NOTE:
1) The figure represents children 3-21 years old served under P.L. 94-142 and children 0-20 years old under P.L. 89-313.

All states, as well as the District of Columbia, have mandated early education services to precede public school services. However, significant variance exists regarding the age range of such initiatives. Figure 23 displays effective age ranges of various state mandates and shows that many offer services to some portion of the population of preschool children with disabilities. New Mexico is included in this group.

In the past, because New Mexico did not participate in P.L. 94-142, it did not receive federal funds to operate its early childhood education programs, relying instead on appropriations from the state legislature. Preschool services were primarily provided by community based agencies under contract with the state's Developmental Disabilities Bureau of the Health and Environment Department (HED). Recently, however, New Mexico has opted to participate in P.L. 94-142 and will receive federal education funds. The impact of this change in funding services may with time alter how early education services are operated.

2. Public School Services

As noted above, New Mexico did not, until recently, participate in P.L. 94-142. It did, however, maintain public school educational services for persons aged 5-21 that were funded through appropriations from the state legislature.

Public school services for persons with developmental disabilities primarily are based on the principle of "mainstreaming." This concept holds that individuals should receive services commensurate with their habilitative needs within least restrictive settings. With regard to habilitative needs, as a child grows older and becomes more skillful, his/her

Figure 23:

Mandates for Serving Handicapped Children Aged Six and Under by State

Source: Division of Education Services
Special Education Programs, 1985

			Age Range		
0-5	2-5	3-5	4-5	5	6
Alaska	Virginia	Connecticut (1)	Minnesota	Alabama	Indiana
Iowa		District of Columbia	——————	Colorado	Montana
Maryland		Hawaii	Delaware (5)	Florida	Oregon
Michigan		Illinois	Oklahoma (6)	Georgia	Pennsylvania
Nebraska		Massachusetts	Tennessee (7)	Idaho	Vermont
New Jersey		New Hampshire	Washington (8)	Kansas	——————
South Dakota		Rhode Island		Kentucky	Arkansas (11)
		Wisconsin		Maine	Arizona (12)
		——————		Missouri	Mississippi (13)
		California (2)		New Mexico	North Dakota (14)
		Louisiana (3)		New York	
		Texas (4)		North Carolina	
				Ohio	
				Utah	
				West Virginia	
				Wyoming	
				——————	
				Nevada (9)	
				South Carolina (10)	

Notes: States with different mandated ages for particular handicapping conditions and States with scheduled changes in mandated age are shown below the dashed line (———).

Numbered Notes: (1) Connecticut: 2.8-all handicapping conditions; (2) California: 3-all handicapping conditions, 0-LEAs that provided services to children from birth to 3 during the 1980-81 school year must continue to do so; (3) Louisiana: 3-all handicapping conditions, 0-children with serious handicapping conditions that, without intervention, will become progressively more difficult for successful intervention by school age; (4) Texas: 3-all handicapping conditions, 0-(VI, HI, DB); (5) Delaware: 4-all handicapping conditions, 3-(TMH, SMH PI), 0-(HI, VI, DB, A); (6) Oklahoma: 4-all handicapping conditions, 0-(VI, HI, SH); (7) Tennessee: 4-all handicapping conditions, 3-(D); (8) Washington: 4-all handicapping conditions, 3-all handicapping conditions as of 1985-86 school year; (9) Nevada: 5-all handicapping conditions, 3-(MH), 0-(AI, VI); (10) South Carolina: 5-all handicapping conditions, 4-(VI, HI, D); (11) Arkansas: 6-all handicapping conditions, 5-if LEA offers kindergarten; (12) Arizona: 6-all handicapping conditions, 5-if LEA offers kindergarten; (13) Mississippi: 6-all handicapping conditions, 5-all handicapping conditions as of 1985-86 school year; (14) North Dakota: 6-all handicapping conditions, 5-all handicapping conditions as of July, 1985.

Legend of State Terms

A - Autistic
AH - Aurally Handicapped
D - Deaf
DB - Deaf-Blind
HI - Hearing Impaired
MH - Mentally Handicapped
PI - Physically Impaired
SH - Severely Handicapped
SMH - Severely Mentally Handicapped
TMH - Trainable Mentally Handicapped
VI - Visually Impaired

needs change. Specific programs vary by child, but primary age programs (6-12 years) tend to focus on teaching academic skills and promoting physical development. As the child ages, and enters secondary (12-18 years) and post secondary (18-21) programs, however, instructors focus more on teaching community life and vocational skills. Within all these programs numerous settings can be utilized including the regular classroom, specialized separate classses, separate schools, the family home, and other environments.

Over four million persons with disabilities receive public school services under P.L. 89-313 and P.L. 94-142. Figure 24 displays by state the number of children aged 3-21 who receive such services. Review of this table reveals that, according to state child count figures, 26,334 children with disabilities reside in New Mexico.

The DES-SES (1984) reports that the number of children with disabilities receiving special education services has increased over the past several years. Overall, between 1976-77 and 1982-83 there was an increase of about 500,000 persons. In the past year alone (1981-82 to 1982-83) there was an increase of 65,045 children. This increase, however, was not evenly distributed among states or disability category.

Figure 25 displays changes in the child count by state and shows that the number of children actually decreased in numerous states. Figure 26 provides a more detailed analysis of these population changes and shows that New Mexico experienced a 73.8% increase in identified children with disabilities from 1976-77 to 1982-83 (11,185 children) and a 7.7% increase from 1981-82 to 1982-1983 (1,1880 children).

Figure 24

NUMBER OF CHILDREN AGES 3-21 YEARS SERVED UNDER P.L. 89-313 AND P.L. 94-142
BY HANDICAPPING CONDITION

DURING SCHOOL YEAR 1982-1983

STATE	ALL CONDITIONS	LEARNING DISABLED	SPEECH IMPAIRED	MENTALLY RETARDED	EMOTIONALLY DISTURBED	OTHER HEALTH IMPAIRED	MULTI-HANDI-CAPPED	HARD OF HEARING & DEAF	ORTHO-PEDICALLY IMPAIRED	VISUALLY HANDI-CAPPED	DEAF-BLIND
ALABAMA	81.809	30.899	16.239	34.988	8.119	401	979	1,138	381	423	54
ALASKA	12,017	6.828	3,374	665	382	58	218	200	243	58	15
ARIZONA	51.882	25.710	11,195	8,002	5.288	662	843	1,043	747	374	0
ARKANSAS	49.004	19.436	10.493	16.013	808	249	753	739	421	269	23
CALIFORNIA	384.318	198.890	92.058	28.580	9.457	14.071	4.776	7.217	7.033	2.203	229
COLORADO	45.128	19.654	7.796	5.795	7.598	0	2.029	1,018	815	331	92
CONNECTICUT	68.010	29.352	13.898	8.208	13.089	918	478	988	383	719	3
DELAWARE	14.405	6.670	1.747	2.115	2.943	125	31	294	311	127	42
DISTRICT OF COLUMBIA	5.809	1.829	1.780	1.237	897	87	94	83	140	43	37
FLORIDA	155.909	58.105	48.258	27.537	17.077	1.569	78	2.086	2.080	770	71
GEORGIA	112.555	35.722	38.782	28.214	17,412	896	358	1,847	913	808	7
HAWAII	12.876	.8.189	1,982	1.514	438	9	187	248	214	63	82
IDAHO	17.873	8.233	4.350	2.948	518	423	298	430	306	181	8
ILLINOIS	261.769	98.805	75.784	44.546	31.884	1.722	1.134	4.198	4.392	1,400	104
INDIANA	100.228	27.434	41.380	24.189	2.775	282	1,458	1,382	818	528	24
IOWA	58.109	21.340	14.858	12.228	4.749	207	757	1,081	853	241	17
KANSAS	44.159	18.190	14.274	6.779	4.323	51	405	771	719	277	370
KENTUCKY	73.170	20.084	24.922	21.741	2.356	608	1.295	943	781	481	19
LOUISIANA	86.009	39.707	20.701	19.742	4.225	1.769	995	1.707	869	489	29
MAINE	28.485	8.974	6.138	5.167	4.225	251	738	403	429	151	11
MARYLAND	90.879	48.368	26.209	7.943	3.598	560	3.239	1,500	828	587	51
MASSACHUSETTS	138.480	48.884	31.848	29.357	18.970	1.939	3.047	1.939	1.525	831	140
MICHIGAN	155.771	55.467	44.081	28.971	20.400	10	187	3.059	6.884	912	0
MINNESOTA	77.858	34.748	19.013	13.789	5.855	868	4	1,635	1,298	419	33
MISSISSIPPI	50.883	16.788	16.798	15.381	422	1	227	635	353	233	47
MISSOURI	99.984	36.224	33.202	19.530	7.017	704	817	1,175	842	390	83
MONTANA	15.219	7.208	4.790	1.515	683	127	323	247	114	183	25
NEBRASKA	30.448	13.227	9.248	5.689	1.887	0	347	514	400	150	8
NEVADA	13.338	7.041	3.232	1.047	790	342	369	175	284	85	1
NEW HAMPSHIRE	14,163	6.220	2.325	1,419	1,197	228	235	278	137	103	5
NEW JERSEY	181.481	62.736	61.280	13.463	15.254	1,508	3.741	2.028	1,213	1,221	37
NEW MEXICO *	28.334	13.237	8.789	2.782	2.164	95	1.248	472	308	134	57
NEW YORK	284.835	118.753	41.861	37.810	44.229	5.913	8.882	5.088	4.347	2.003	158
NORTH CAROLINA	120.588	49.019	25.808	33.240	5.999	1,188	1,680	2.305	1.015	892	42
NORTH DAKOTA	10.802	4.340	3.800	1,920	297	113	0	257	181	80	14
OHIO	202.234	72.031	58.932	58.802	8.302	0	2.815	2.783	3.538	983	48
OKLAHOMA	65.819	28.829	20.389	13.582	1.039	228	1.291	852	434	338	41
OREGON	48.201	23.499	11.814	4.781	2.565	569	118	1,408	933	713	63
PENNSYLVANIA	195.277	83.412	61.884	40.402	18.859	8	5	4.165	3.119	1,813	9
PUERTO RICO	35.173	1.892	1.208	21.159	795	3.099	2.592	2.237	522	2.898	95
RHODE ISLAND	18.989	11.729	3.337	1,498	1,185	210	109	240	221	67	17
SOUTH CAROLINA	71.709	30.930	19.598	22.404	5.710	150	432	1,191	801	488	13
SOUTH DAKOTA	11.841	3.583	5.413	1,481	320	80	392	304	234	80	14
TENNESSEE	108.091	42.804	32.998	20.245	2.853	1.452	1.729	2.186	1.082	717	27
TEXAS	289.343	150.798	68.544	30.769	17,707	5.485	7.528	4.888	3.525	1,989	172
UTAH	38.988	13.811	8.375	3.159	10.623	234	1,458	829	283	351	45
VERMONT	9.309	2.972	2.895	2.563	393	118	196	206	120	44	3
VIRGINIA	100.713	38.614	30.703	18.878	8.723	469	3.090	1.615	719	1,879	27
WASHINGTON	64.295	31.288	13.511	9.400	3.949	1.536	1.740	1.385	1.070	380	38
WEST VIRGINIA	42.418	14.719	13.774	11.068	1.412	923	328	490	393	313	2
WISCONSIN	72.219	27.224	18.024	13.234	9.598	505	699	1.245	1.195	451	44
WYOMING	11,144	5.095	3.184	943	978	227	317	127	177	75	21
AMERICAN SAMOA	244	1	50	181	0	2	9	13	2	3	3
GUAM	2,031	530	243	913	83	12	119	87	19	32	13
NORTHERN MARIANAS	-	-	-	-	-	-	-	-	-	-	-
TRUST TERRITORIES	-	-	-	-	-	-	-	-	-	-	-
VIRGIN ISLANDS	1,237	220	245	626	25	0	29	47	11	12	12
BUR. OF INDIAN AFFAIRS	4,849	2.531	1.047	723	251	33	199	34	17	14	0
U.S. AND TERRITORIES	4,298,327	1,745,871	1,134,197	780,831	353,431	52,026	65,479	75,337	57,506	31,096	2,553

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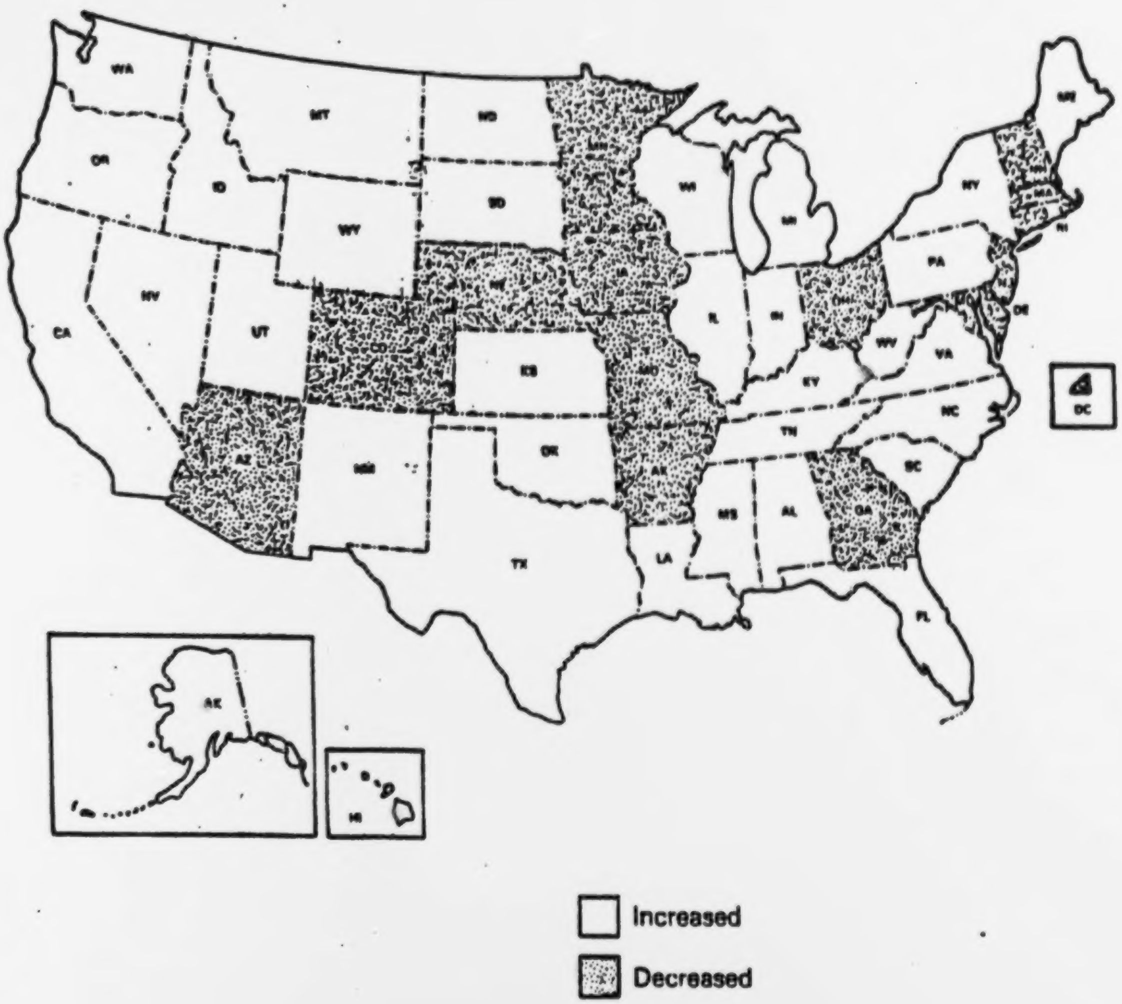
* THESE ARE NEW MEXICO'S CHILD COUNT FIGURES. HOWEVER, NEW MEXICO DOES NOT PARTICIPATE IN P L. 94-142.

*Source: Division of Educational Services, Special Education Programs. Sixth annual report to Congress on the implementation of Public Law 94-142: The Education for all Handicapped Children Act. Washington, DC: US Department of Education, Office of Special Education and Rehabilitation Services, 1984.

Figure 25 Change in Number of Handicapped Children Ages 3-21 Reported in Child Count Between 1981-82 and 1982-83



NOTES:

The number of handicapped children reported decreased for Guam and the Bureau of Indian Affairs.

The number of handicapped children reported increased for Puerto Rico, American Samoa, and The Virgin Islands.

No data were available for the Northern Marianas and the Trust Territories.

*Source: Division of Educational Services, Special Education Programs. Sixth annual report to Congress on the implementation of Public Law 94-142: The Education for all Handicapped Children Act. Washington, DC: US Department of Education, Office of Special Education and Rehabilitation Services, 1984.

Figure 26

NUMBER AND CHANGE IN NUMBER OF CHILDREN AGES 3-21 YEARS SERVED UNDER P.L. 89-313 AND P.L. 94-142

ALL CONDITIONS

STATE	NUMBER 1976-77	NUMBER 1981-82	NUMBER 1982-83	CHANGES IN NUMBER SERVED 1982-83 - 1976-77	CHANGES IN NUMBER SERVED 1982-83 - 1981-82	PERCENT CHANGE IN NUMBER SERVED 1982-83 - 1976-77	PERCENT CHANGE IN NUMBER SERVED 1982-83 - 1981-82
ALABAMA	53,987	76,397	81,609	27,622	5,212	51.2	6.8
ALASKA	9,597	11,007	12,017	2,420	1,010	25.2	9.2
ARIZONA	43,045	52,137	51,862	8,817	-275	20.5	-0.5
ARKANSAS	28,487	49,863	49,004	20,518	-859	72.0	-1.7
CALIFORNIA	332,291	359,888	364,318	32,027	4,430	9.6	1.2
COLORADO	47,943	46,147	45,126	-2,817	-1,021	-5.9	-2.2
CONNECTICUT	62,085	66,311	66,010	3,926	-301	6.3	-0.5
DELAWARE	14,307	14,440	14,405	98	-35	0.7	-0.2
DISTRICT OF COLUMBIA	9,261	6,129	5,809	-3,452	-320	-37.3	-5.2
FLORIDA	117,257	149,838	155,609	38,352	5,771	32.7	3.9
GEORGIA	85,209	115,779	112,555	27,346	-3,224	32.1	-2.8
HAWAII	10,544	12,678	12,876	2,332	198	22.1	1.6
IDAHO	14,573	17,154	17,673	3,101	519	21.3	3.0
ILLINOIS	229,797	255,795	261,769	31,972	5,974	13.9	2.3
INDIANA	87,644	97,847	100,228	12,584	2,381	14.4	2.4
IOWA	51,055	56,894	56,109	5,054	-785	9.9	-1.4
KANSAS	37,623	42,544	44,159	6,537	1,615	17.4	3.8
KENTUCKY	57,057	72,057	73,170	16,113	1,113	28.2	1.5
LOUISIANA	88,989	83,879	88,009	-980	4,130	-1.1	5.0
MAINE	22,701	24,947	25,485	2,784	538	11.7	2.1
MARYLAND	84,184	93,296	90,879	6,695	-2,417	8.0	-2.6
MASSACHUSETTS	131,992	139,747	138,480	6,488	-1,267	4.9	-0.9
MICHIGAN	153,112	154,061	155,771	2,659	1,710	1.7	1.1
MINNESOTA	72,136	77,916	77,658	5,522	-258	7.7	-0.3
MISSISSIPPI	29,219	49,456	50,883	21,665	1,427	74.1	2.9
MISSOURI	94,387	100,931	99,984	5,597	-947	5.9	-0.9
MONTANA	8,610	14,279	15,215	6,605	936	76.7	6.6
NEBRASKA	25,270	31,812	30,448	5,178	-1,364	20.5	-4.3
NEVADA	11,133	12,456	13,326	2,193	870	19.7	7.0
NEW HAMPSHIRE	9,916	14,179	14,143	4,227	-36	42.6	-0.3
NEW JERSEY	145,077	163,686	161,481	16,404	-2,205	11.3	-1.3
NEW MEXICO	15,149	24,454	26,334	11,185	1,880	73.8	7.7
NEW YORK	240,250	250,404	264,835	24,585	14,431	10.2	5.8
NORTH CAROLINA	98,035	120,041	120,586	22,551	545	23.0	0.5
NORTH DAKOTA	8,978	10,212	10,802	1,828	590	20.3	5.8
OHIO	168,314	210,445	202,234	33,920	-8,211	20.2	-3.9
OKLAHOMA	44,181	65,479	65,819	21,638	340	49.0	0.5
OREGON	37,258	45,278	46,201	8,943	923	24.0	2.0
PENNSYLVANIA	206,792	190,919	196,277	-10,515	5,358	-5.1	2.8
PUERTO RICO	11,200	27,852	35,173	23,973	7,321	214.0	26.3
RHODE ISLAND	15,971	18,435	18,589	2,618	154	16.4	0.8
SOUTH CAROLINA	72,357	69,476	71,705	-652	2,229	-0.9	3.2
SOUTH DAKOTA	9,936	11,522	11,841	1,905	319	19.2	2.8
TENNESSEE	99,251	102,459	106,091	6,841	3,632	6.9	3.5
TEXAS	233,552	281,873	289,343	55,791	7,470	23.9	2.7
UTAH	37,204	37,584	38,968	1,764	1,384	4.7	3.7
VERMONT	6,383	11,563	9,309	2,926	-2,254	45.9	-19.5
VIRGINIA	77,616	99,571	100,713	23,097	1,142	29.8	1.1
WASHINGTON	57,705	63,916	64,295	6,590	379	11.4	0.6
WEST VIRGINIA	30,135	39,554	42,418	12,283	2,864	40.8	7.2
WISCONSIN	58,019	71,593	72,219	14,200	626	24.5	0.9
WYOMING	7,281	10,844	11,144	3,863	300	53.1	2.8
AMERICAN SAMOA	138	204	244	106	40	78.3	19.6
GUAM	2,597	2,123	2,031	-566	-92	-21.8	-4.3
NORTHERN MARIANAS	-	-	-	-	-	-	-
TRUST TERRITORIES	1,120	-	-	-	-	-	-
VIRGIN ISLANDS	1,712	272	1,237	-475	965	-27.7	354.8
BUR. OF INDIAN AFFAIRS	-	4,859	4,849	-	-10	-	-0.2
U.S. AND TERRITORIES	3,708,588	4,233,282	4,298,327	589,739	65,045	15.9	1.5

*Source: Division of Educational Services, Special Education Programs. _Sixth annual report to Congress on the implementation of Public Law 94-142: The Education for all Handicapped Children Act._ Washington, DC: US Department of Education, Office of Special Education and Rehabilitation Services, 1984.

Likewise, increases in child counts are not evenly distributed across disability categories. The left side of Figure 27 shows that children with learning disabilities and emotional disturbances increased in number while numbers of children in all other categories declined.

As noted earlier, children with disabilities are served within a variety of settings. The right side of Figure 27 displays the relative usage of four education environments for persons aged 3-21 and shows that the primary service setting is the regular classroom (67.55%). This finding is not surprising given that the disability category most often served in public schools is learning disabilities, a relatively mild handicapping condition (national percentage is 40% -- see Figure 26). No figures regarding the use of various educational settings are available for New Mexico from the U.S. Department of Education. However, because New Mexico reports a relatively high proportion of its children with disabilities as having a learning disability (46%), it can be speculated that the state would also utilize the regular classroom as a primary educational setting.

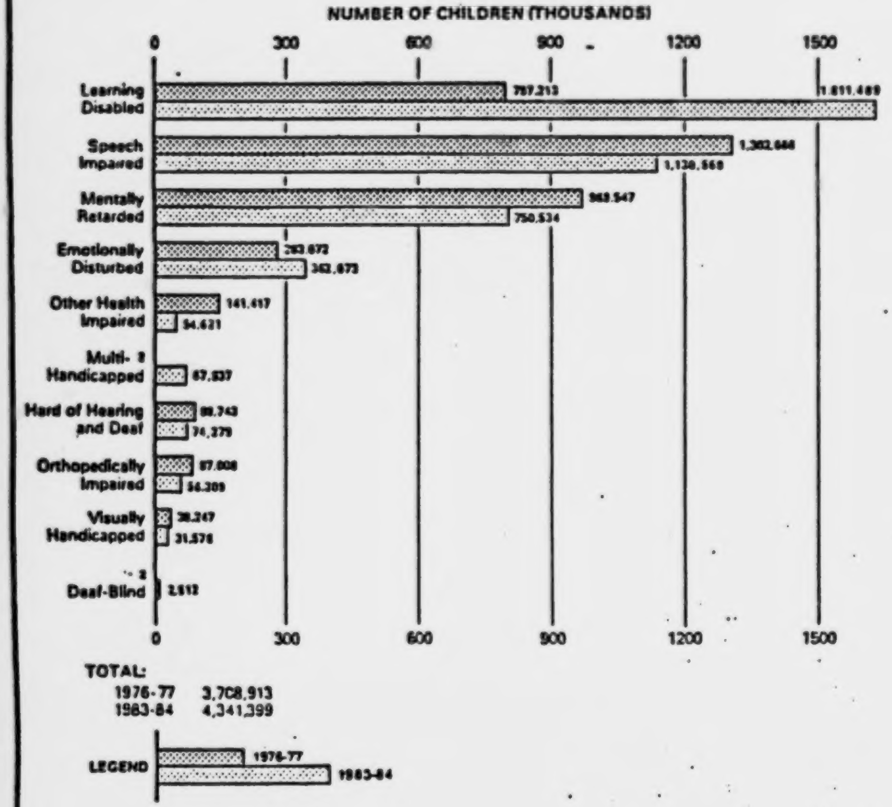
D. Vocational Services

1. Program Goals

A normal life rhythm for persons not occupied with domestic tasks involves leaving their homes during the day to participate in some activity. For most, the primary day activity revolves around employment. Predictably, the current trend to provide community services for persons with developmental disabilities has spurred creation of specialized vocational opportunities so that these persons also may engage in productive vocational activity within maximally integrated settings.

Figure 27: Distribution of Children Served Under P.L. 89-313 and P.L. 94-142 by Handicapping Condition, School Years 1976-77 and 1983-84 1

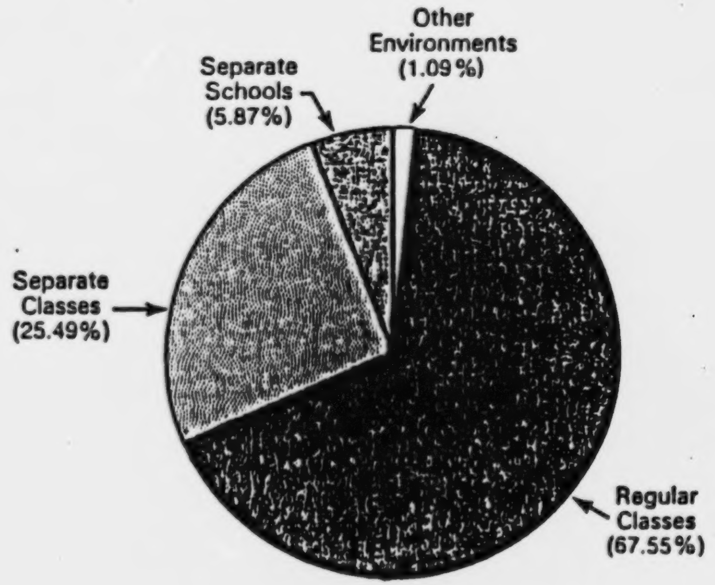
Source: Division of Education Services Office of Special Education Programs, 1985



NOTES:
1) The figure represents children 3-21 years old served under P.L. 94-142 and children 0-20 years old under P.L. 89-313.

2) Data not available for 1976-77.

Figure 27 Percent of Handicapped Children Served (Ages 3-21) in Four Educational Environments, School Year 1982-83



In New Mexico, a modest range of vocational services exists including:

- Work Activity-Work Adjustment. A structured program of activities provided in a facility or client's home that emphasizes the development of adjustment to work rather than the development of a particular skill; and
- Sheltered Workshops. A structured program of activities provided in a facility or in a client's home that stresses work evaluaiton, work adjustment, occupational skill training and short-term renumerative employment" (Continuing Care/Disabled under 65, Chapter 11, p. 58).

The primary purpose of these services is to provide persons with developmental disabilities vocational instruction and opportunity with the intent of enabling these persons to function in as culturally normative a work setting as possible. This is achieved through structured vocational instruction and by providing individuals with actual employment opportunity.

2. National Perspective and New Mexico.

The advent of P.L. 94-142 has done much to make day time education services available to school aged persons with disabilities. There is, however, no similarly clear mandate for providing vocational services. As a result, once a person with developmental disabilities "ages out" of the public school system (i.e., turns 21 years old), the availability of day services becomes uncertain.

Numerous studies have shown that persons with developmental disabilities living in a variety of residential settings often are not involved with any structured day activity outside the home. Figure 28 displays the primary day placement of persons with mental retardation living within private community residential alternatives according to a 1978-79 national probability sample (White, Hill, Lakin & Bruininks, 1984). Review of this table reveals that nearly 2 of 10 adults had no day program.

Figure 28: Primary Day Placement of Adults with Mental Retardation Living in Community Residential Alternatives (national probability sample)

Day Placement	Percent of Residents
Work Placement	47%
Day Activity Center	29%
Home Based Programs	4%
Other	3%
No Day Program	17%
Total	100%

In New Mexico, recent estimates pertaining to all adults with developmental disabilities living in the community (including those living with their family) show that only 23% of these adults attend a day program (See Part Two; Section II).

In recent years state and federal policy makers have placed the need for increased numbers of day service options among its higher priorities. The problem, however, is aggravated annually due to the inevitable graduation of special education students from post-secondary public school programs. Figure 29 shows the number of children aged 18-21 currently served under P.L. 94-142. Based on these numbers, it can be anticipated that approximately 170,000 children will be graduating from public school services across the country in the next three years (about 1000 of these persons live in New Mexico). Many of these young adults will require specialized vocational services.

Further, pursuing models that focus on maximum community integration, numerous analysts are calling for a decreased reliance on segregated programs (e.g., work activity centers, sheltered workshops), urging development of integrated

Figure 29

NUMBER OF CHILDREN AGES 18-21 YEARS SERVED UNDER P.L. 94-142
BY HANDICAPPING CONDITION

DURING SCHOOL YEAR 1982-1983

STATE	ALL CONDITIONS	LEARNING DISABLED	SPEECH IMPAIRED	MENTALLY RETARDED	EMOTIONALLY DISTURBED	OTHER HEALTH IMPAIRED	MULTI-HANDI-CAPPED	HARD OF HEARING & DEAF	ORTHO-PEDICALLY IMPAIRED	VISUALLY HANDI-CAPPED	DEAF-BLIND
ALABAMA	5,237	1,015	39	3,616	323	46	102	47	38	11	2
ALASKA	292	186	7	49	13	3	9	14	8	1	0
ARIZONA	2,215	946	38	809	187	106	49	48	28	9	0
ARKANSAS	1,400	599	20	729	7	2	10	18	11	3	1
CALIFORNIA	19,763	6,006	900	9,330	993	746	718	514	394	142	20
COLORADO	1,637	673	7	443	359	0	84	61	32	3	1
CONNECTICUT	5,403	1,708	78	1,299	1,979	119	48	113	52	2	3
DELAWARE	497	323	1	119	99	4	1	4	1	3	7
DISTRICT OF COLUMBIA	33	17	9	0	0	0	0	1	0	0	0
FLORIDA	4,991	1,892	208	2,477	317	94	6	173	96	13	14
GEORGIA	3,447	871	49	2,068	278	16	6	101	41	19	2
HAWAII	287	164	4	93	10	0	3	8	5	0	0
IDAHO	697	0	1	70	27	288	188	25	110	10	2
ILLINOIS	7,628	2,789	287	2,880	1,446	68	43	39	61	27	6
INDIANA	2,383	787	120	1,334	51	2	28	25	31	3	1
IOWA	2,849	1,023	48	1,318	194	25	125	52	51	10	5
KANSAS	1,682	336	157	680	305	0	0	28	39	5	28
KENTUCKY	2,221	647	37	1,276	78	32	71	41	26	12	1
LOUISIANA	3,138	1,178	62	1,624	83	56	49	58	14	12	2
MAINE	1,050	370	29	393	144	22	55	16	13	8	0
MARYLAND	4,594	1,876	205	1,434	241	49	597	78	64	8	2
MASSACHUSETTS	5,341	1,869	1,226	1,132	732	75	118	75	59	32	5
MICHIGAN	6,819	2,666	119	2,487	794	0	71	240	364	78	0
MINNESOTA	3,080	1,220	37	1,434	262	18	0	40	38	11	2
MISSISSIPPI	2,180	701	52	1,364	8	0	10	19	20	4	2
MISSOURI	3,019	978	111	1,431	281	32	89	41	70	9	0
MONTANA	530	292	18	155	21	4	28	8	4	2	0
NEBRASKA	1,406	552	24	659	80	0	32	42	23	14	0
NEVADA	546	352	11	104	16	19	15	15	4	10	0
NEW HAMPSHIRE	471	324	4	97	32	4	6	0	4	0	0
NEW JERSEY	5,298	2,065	193	1,624	795	104	254	165	73	22	3
NEW MEXICO *	1,113	522	56	348	72	1	83	12	10	7	2
NEW YORK	11,732	3,891	176	4,562	2,003	265	202	363	173	97	0
NORTH CAROLINA	5,161	1,711	91	3,027	129	57	48	62	49	39	1
NORTH DAKOTA	344	137	9	175	5	2	0	5	8	3	0
OHIO	6,289	1,746	209	3,383	237	0	210	247	211	43	3
OKLAHOMA	1,527	774	15	665	14	2	13	29	11	4	0
OREGON	1,593	707	50	388	137	93	0	31	178	9	0
PENNSYLVANIA	9,513	3,806	396	3,473	654	2	0	258	130	98	0
PUERTO RICO	7,650	33	218	4,080	19	834	391	744	33	1,338	4
RHODE ISLAND	796	432	6	243	59	8	8	21	11	9	1
SOUTH CAROLINA	3,013	624	80	2,035	129	5	19	59	48	17	1
SOUTH DAKOTA	473	179	51	155	15	12	40	12	9	0	0
TENNESSEE	5,665	2,308	110	2,397	238	123	219	122	110	38	3
TEXAS	9,379	5,526	77	2,503	480	197	315	38	170	67	4
UTAH	733	102	21	211	178	5	199	6	6	1	4
VERMONT	184	87	9	62	6	7	3	6	3	1	0
VIRGINIA	4,105	1,214	176	2,075	255	22	225	68	41	28	1
WASHINGTON	2,392	1,034	124	860	125	66	111	38	24	9	1
WEST VIRGINIA	1,633	489	76	938	39	24	16	14	28	9	0
WISCONSIN	3,399	1,138	59	1,565	390	28	65	79	58	16	5
WYOMING	339	183	1	92	40	4	9	3	2	4	1
AMERICAN SAMOA	19	0	0	14	0	0	0	3	0	2	0
GUAM	81	27	2	46	0	1	0	1	4	0	0
NORTHERN MARIANAS	-	-	-	-	-	-	-	-	-	-	-
TRUST TERRITORIES	-	-	-	-	-	-	-	-	-	-	-
VIRGIN ISLANDS	99	0	8	91	0	0	0	0	0	0	0
BUR. OF INDIAN AFFAIRS	323	159	23	89	35	2	32	1	3	3	0
U.S. AND TERRITORIES	173,842	80,468	5,780	73,974	16,768	3,881	4,925	4,325	3,286	2,308	149

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* THESE ARE NEW MEXICO'S CHILD COUNT FIGURES. HOWEVER, NEW MEXICO DOES NOT PARTICIPATE IN P.L. 94-142.

*Source: Division of Educational Services, Special Education Programs. _Sixth annual report to Congress on the implementation of Public Law 94-142: The Education for all Handicapped Children Act._ Washington, DC: US Department of Education, Office of Special Education and Rehabilitation Services, 1984.

vocational options instead (e.g., affirmative industry, supported employment) (Wehman & Hill, 1985).

Figure 30 shows the results of a recent national survey of day and vocational programs (Buckley & Bellamy, 1984). With 43 states responding, this figure shows that segregated facilities remain more numerous and serve more persons than integrated options. Integrated alternatives, however, are gaining in popularity across the country as their utility is demonstrated for all persons with disabilities, including those whose disabilities are severe, as well as in areas with depresessed economies (Rusch, 1986; Rhodes & Valenta, 1985; Wehman & Hill, 1985).

Figure 30: Number of Programs and Participants Per Program Classification (Source: Buckley & Bellamy, 1984)

Program Classification	Number of Programs	Number of Participants
Adult Day Programs	3,078	135,945
Sheltered Work Programs	1,572	44,119
Integrated Work	460	5,472

* Note: Data are population projections based on responses from 40 states.

The above considerations suggest that as the community system is expanded, New Mexico cannot ignore the present and growing need for specialized vocational services. In a previous section the need for community residential options was detailed. It must be understood that as services are developed to accommodate those needs, complementary day services, reflecting contemporary practice, must also be initiated. Moreover, these day services also must be prepared to serve persons leaving the public school system.

E. The Allocation of Funds

1. The National Perspective

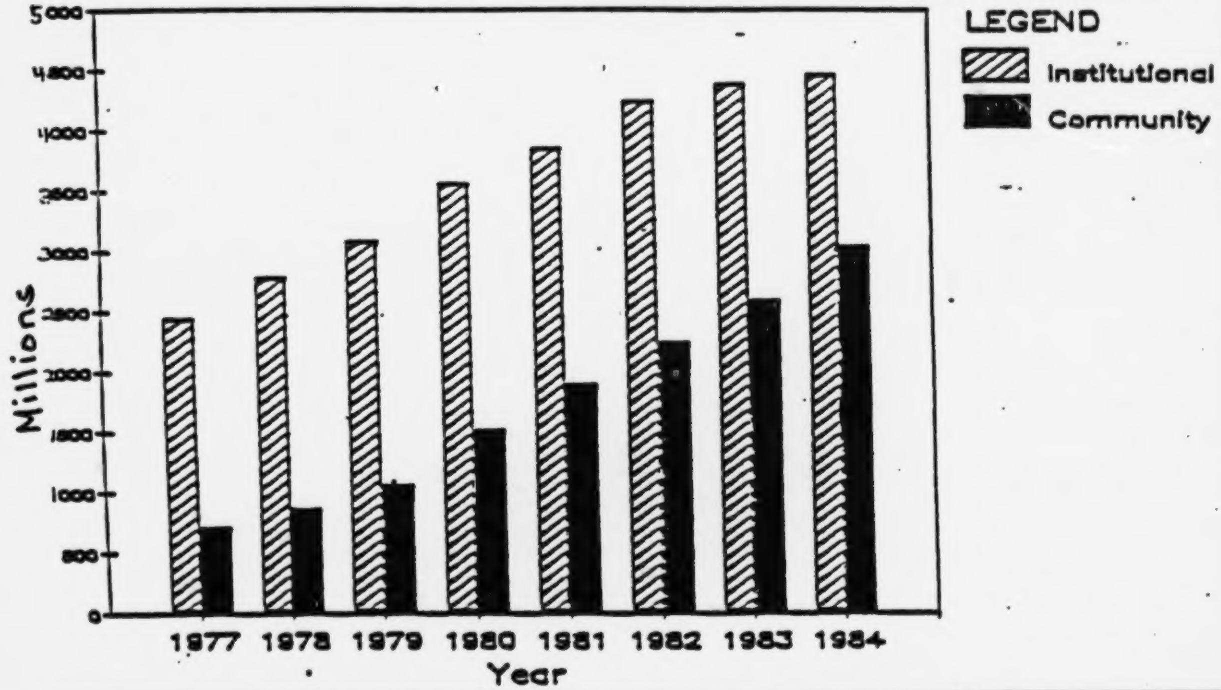
a. Overall Expenditures. Each year more dollars are spent on institutional systems than on community services systems (excluding public school expenditures). The gap, however, is closing slowly. Figure 31 substantiates this point by showing that institutional expenditures are slowly declining (in 1977 dollars) while community expenditures are steadily increasing. Further, Figure 32 shows that the ratio of institutional to community expenditures has fallen from 3.46:1 in 1977 to 1.47:1 in 1984.

Shifts in resources are not uniformly reflected across states. Of course, this finding is not surprising given that states have initiated community-based services with varying levels of interest. Figure 33 displays a comparison of institutional and community services expressed as percentages of total MR/DD expenditures from 1977-1984. According to this figure, in relation to the institution, Nebraska, Colorado and Minnesota have the most developed community service system, while Oklahoma, Delaware and South Carolina have the least developed. New Mexico ranks 35th.

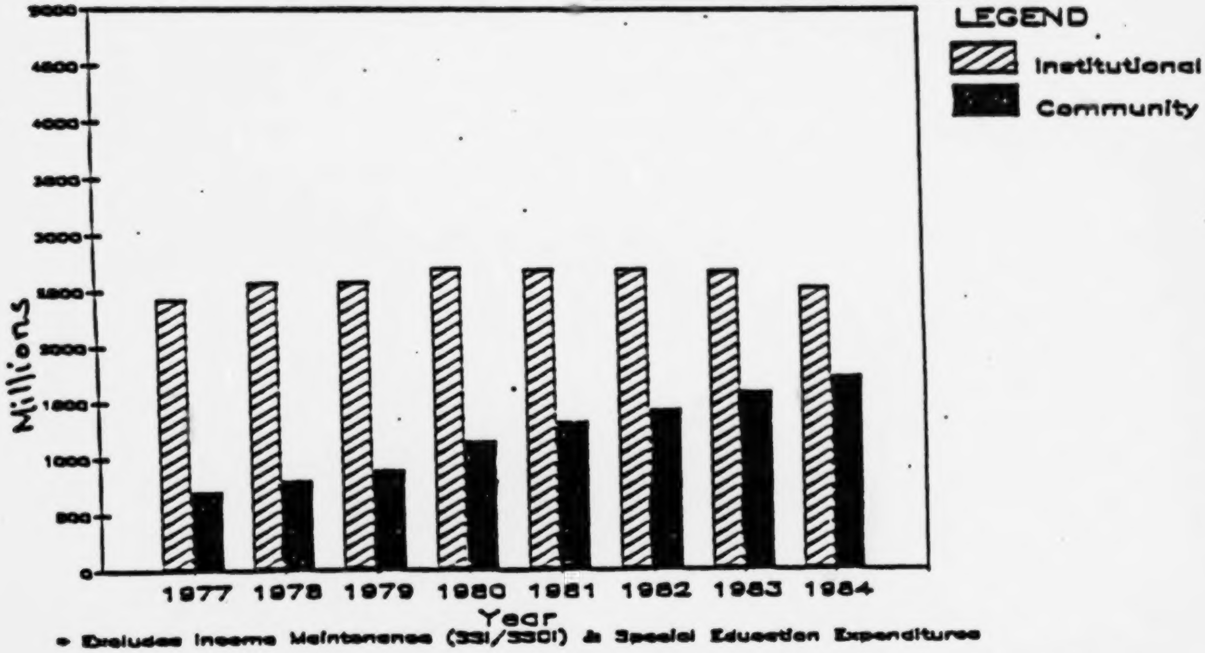
b. Funding Sources. Services for persons with developmental disabilities are funded through a variety of sources including state revenue, Federal Title XX funds and Federal ICF/MR (Title XIX) funds. Figure 34 displays the relative contributions of these various sources for the institutional and community care systems from 1977-1984. Review of this figure reveals that the primary source of funds is state revenue, but that community services rely on state funds more than institutions (70% to 61.4%). Moreover, to supplement state funds, institutional systems receive much support from the

Figure 31

UNITED STATES
Comparative Annual MR/DD Expenditures for *Institutional* & *Community** Services
FY 1977–1984, *In Unadjusted Dollars*



FY 1977–1984, *In 1977 Dollars*



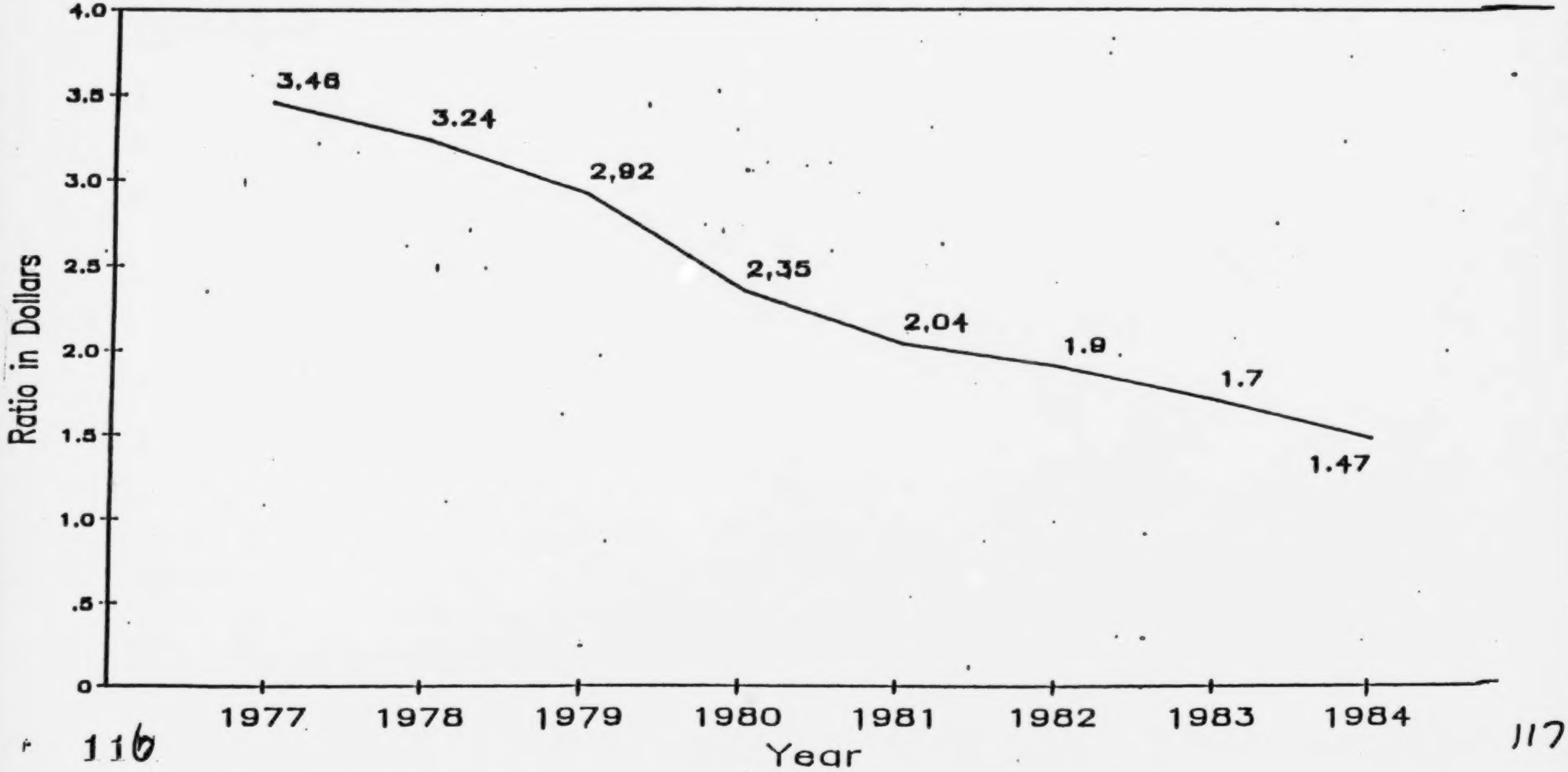
* Excludes Income Maintenance (SSI/SSDI) & Special Education Expenditures

Source: Braddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

Figure 32

UNITED STATES

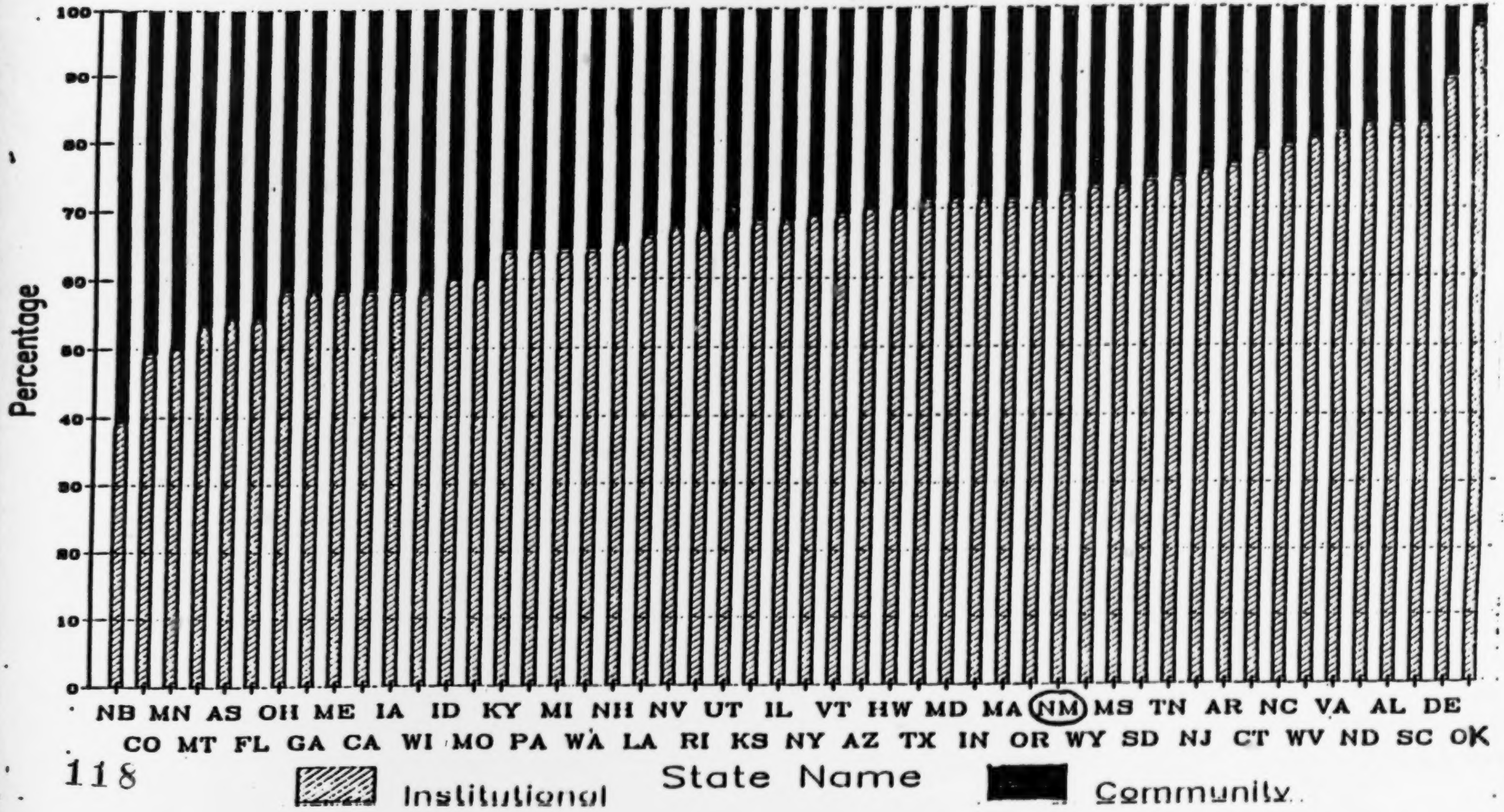
Ratio of MR/DD Institutional Expenditures Per Dollar of Community Services Funding: FY 1977–1984
(Includes State General Funds, ICF/MR Reimbursements, & Title XIX



Source: Braddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

Figure 33

Institutional & Community Services Expressed as Percentages of Total MR/DD Expenditures FY 1977–1984

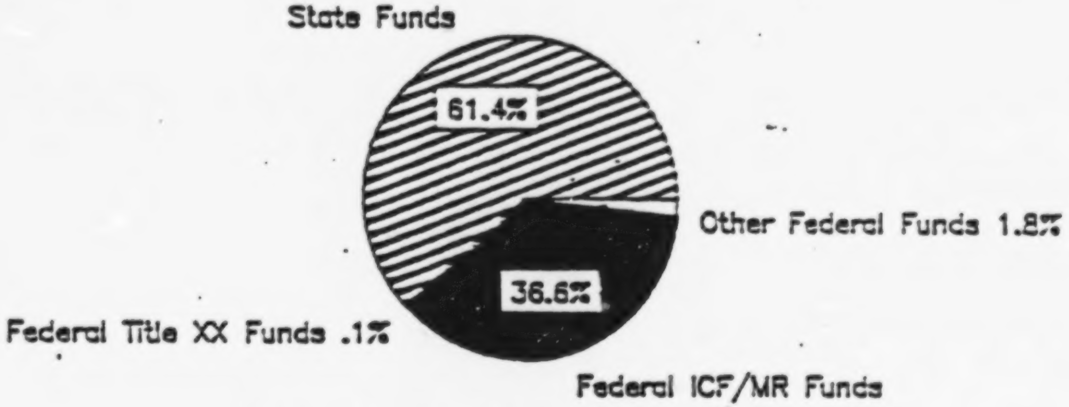


Source: Braddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

Figure 34

UNITED STATES
Eight Year Total MR/DD Expenditures By Revenue Source: FY 1977–1984

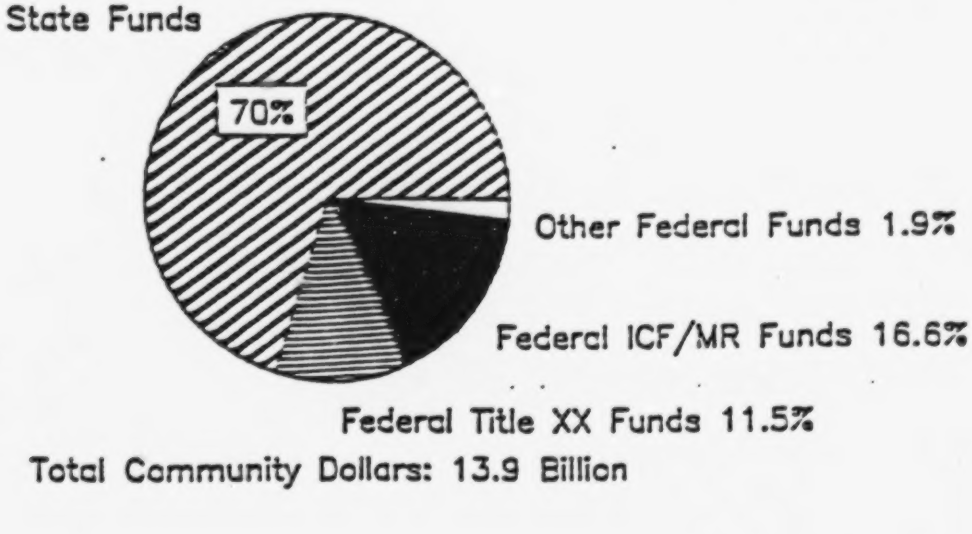
Institutional Services Funds



Total Institutional Dollars: $ 28.9 Billion

Community Services Funds

(Excludes Income Maintenance (SSI/SSDI) & Special Education Expenditures)



Total Community Dollars: 13.9 Billion

Source: Braddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

federal ICF-MR program (36.6%) and very few Title XX dollars (.1%). In contrast, community services receive some support from the ICF-MR program (16.6%) and some from the federal Title XX program (11.5%).

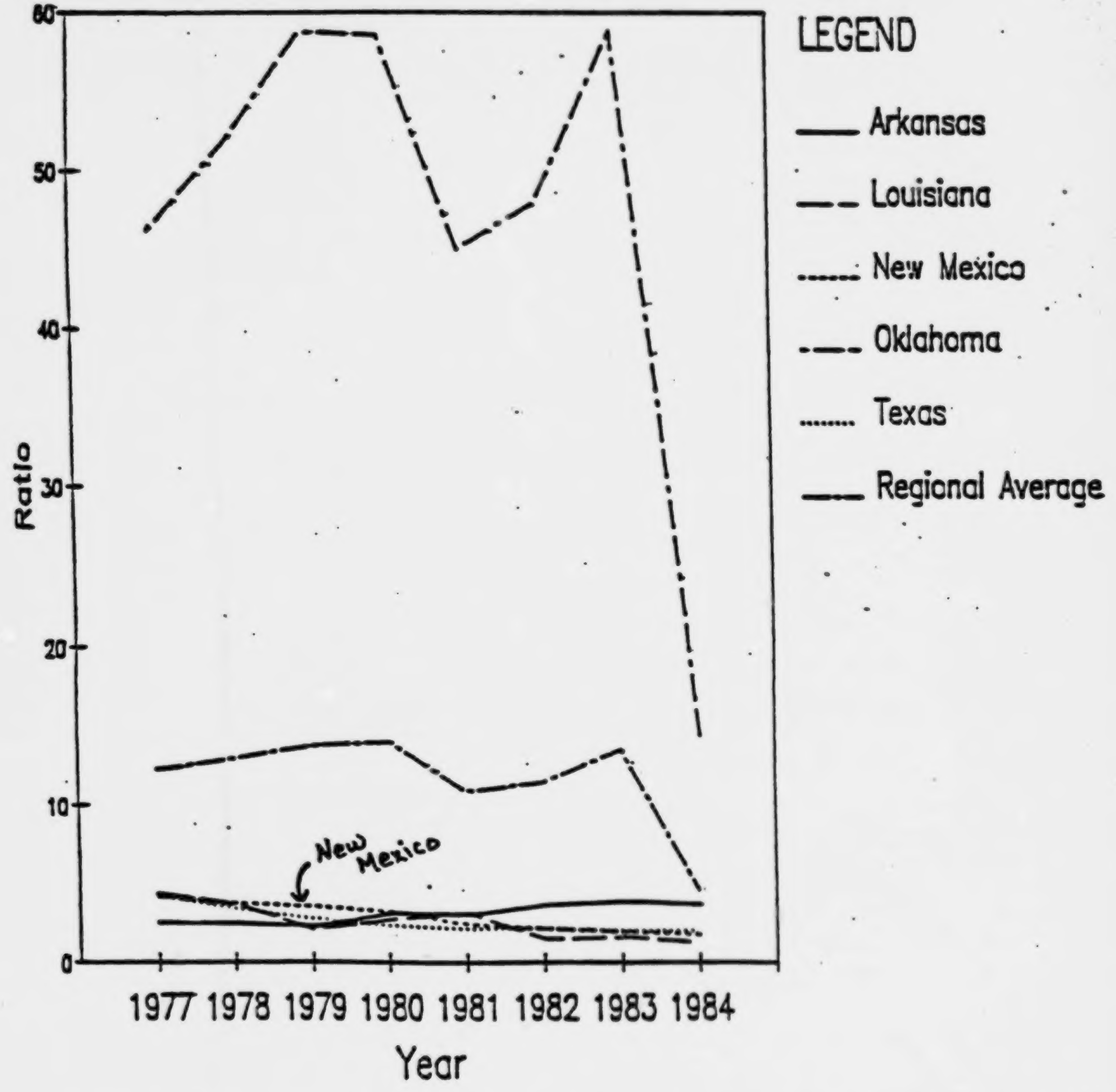
2. Expenditure Patterns in New Mexico

New Mexico is not unlike many of its neighboring states. New Mexico has been assigned to Region Six by the U.S. Department of Health and Human Services along with four other states including Arkansas, Louisana, Oklahoma, and Texas. Figure 35 displays the ratio of MR/DD institutional and community expenditures for each state from 1977-1984. Review of this figure suggests that, like other states in its region, New Mexico has made some progress in narrowing the ratio of institutional to community expenditures. Figure 36 further substantiates this point. Review of this figure reveals slight recent decreases in institutional expenditures (in 1977 dollars), but steady increases in funds expended for community services.

These findings, however, must be viewed in light of the national picture. As shown in Figure 37, compared to the other nine federal service regions, Region Six has the highest ratio of institutional to community services expenditures. Moreover, recall that Figure 19 shows that New Mexico ranks 35th among all states with regard to the precentage it expends on community services as opposed to institutional services. Given these considerations, it is clear that though New Mexico has committed itself to expanding its community based system, much can still be done with regard to shifting fiscal resources from the institution to the community.

Figure: 35

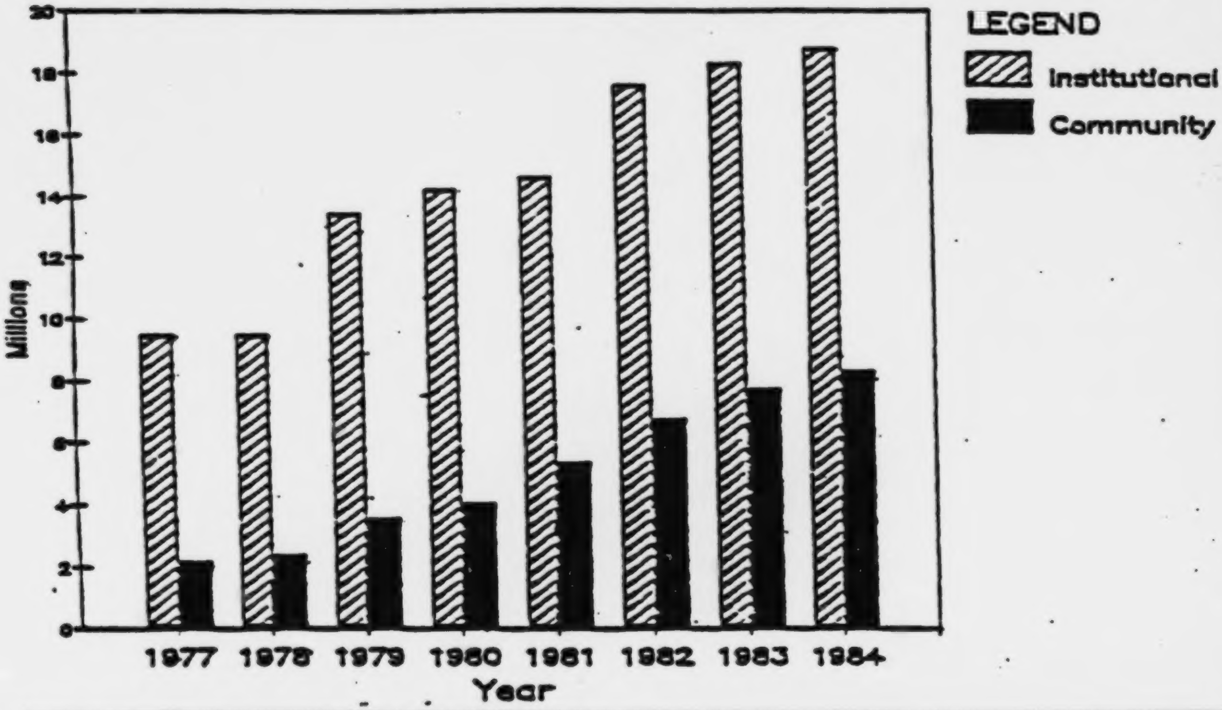
Region 6 (Dallas)
Ratio of MR/DD Institutional and Community Expenditures for Each State and the Regional Average: FY 1977–1984



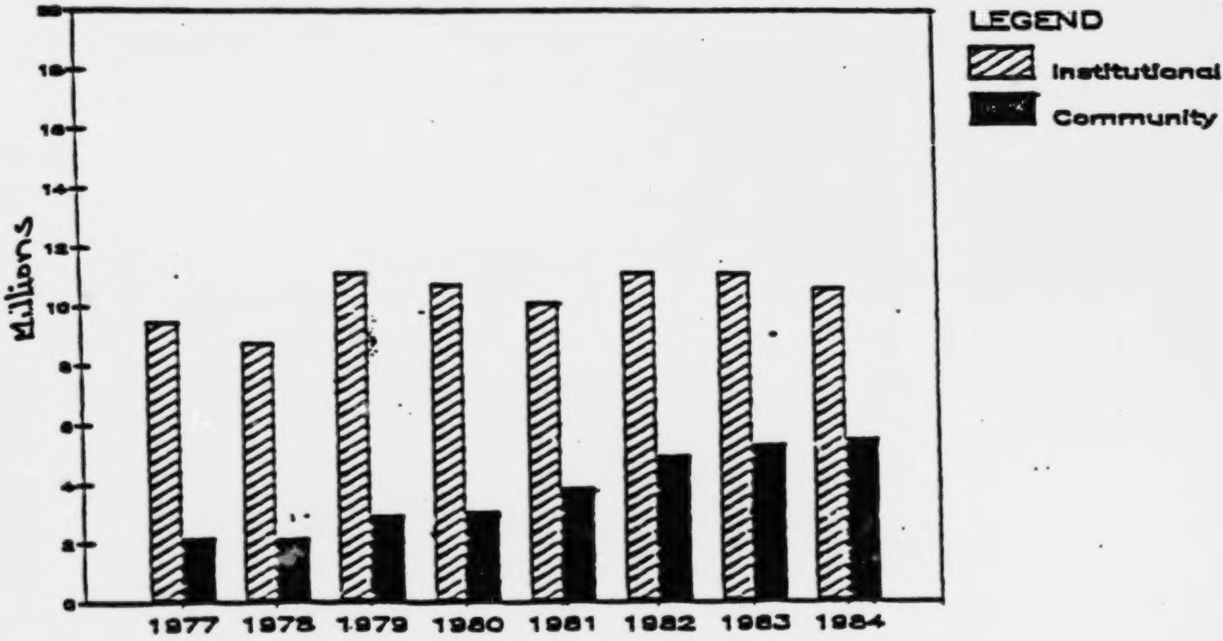
Source: Braddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

Figure 36

NEW MEXICO
Comparative Annual MR/DD Expenditures for Institutional & Community Services
FY 1977–1984, *In Unadjusted Dollars*



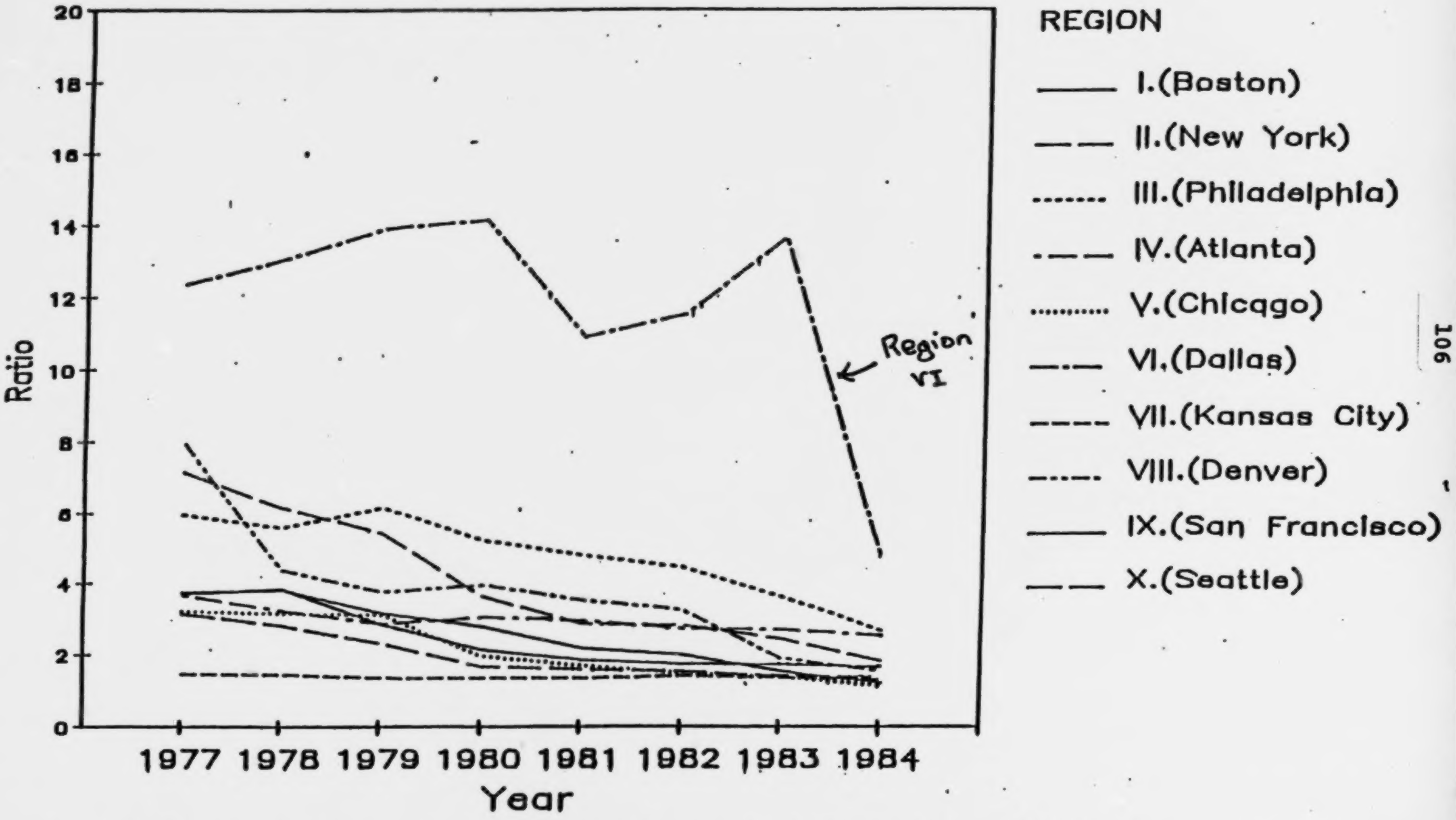
FY 1977–1984, *In 1977 Dollars*



Source: Braddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

Figure 37

Ratio of MR/DD Institutional and
Community Expenditures for Each Region
FY 1977–1984



Source: Braddock, Howes, & Hemp, Expenditure Analysis Project, ISDD, U of IL at Chicago, 1984

PART TWO

PART II
RESIDENTIAL PLAN

Overall Planning Goals

The primary purpose of this plan is to address the need for residential services in New Mexico. In essence, the Institute recommends that current approaches to providing residential care in New Mexico be revised. In light of advances in the state-of-the-art in the provision of services to persons with developmental disabilities and an emerging consensus regarding the values that should govern such services, the Institute advises that the state accommodate the demand for residential services by:

- strengthening the community based system so that a range of residential and support service options are available, and staff are properly prepared;
- de-emphasizing reliance on large centralized facilities such as Fort Stanton and Los Lunas, as well as larger community facilities; and
- establishing means for supporting and enhancing the efforts of families who provide home care to persons with developmental disabilities.

These goals form the backdrop for the ensuing planning objectives and reflect a vision of the future regarding services for persons with developmental disabilities in New Mexico. The following sections provide additional background information pertaining to the foundations and assumptions that guided the preparation of the plan.

1. System Infrastructure

Over the past several years, the reform of service systems has too often moved forward without the establishment of the infrastructure to support changes in service approach and practice. The negative consequences of such decisions, however, well intended, are well documented. Systems with a weak infrastructure lack the capability to systematically improve or expand services, frustrating state officials as well as service providers. Ultimately, the system's capacity for achieving desired ends is compromised, to the dismay of all concerned parties.

Crucial to assuring the success of the proposed plan is the development of an underlying base of personnel, facilities, equipment and administrative structures for supporting the service reform process and any new services that emerge for the long term. As described in greater detail in subsequent sections, the needed infrastructure should include at least:

- An improved client information system;
- An expanded case management system;
- A means for monitoring and assuring the quality of provided services;
- A sub-state planning structure;
- An improved system for preparing and training direct care staff;
- A means for providing specialized services to persons residing in rural areas;
- Systems for coping with crises in residential programs;
- A clear division of interagency roles with regard to delivering services, securing funds and long range planning; and
- An equitable means for setting the costs of services and means for reimbursing providers.

2. Client Directed Support Service Requirements

Save their particular handicaps, persons with developmental disabilities are no different from anyone else. All require shelter, food, and clothing. In the event they become ill, they require the services of health practitioners. To the extent that their impairments limit their ability to care for themselves, move about, and carry on activities of daily living, education and vocational pursuits, they require supervision and support. At the same time, in the interests of both the individual and society, persons with disabilities should be afforded the opportunity to learn those skills necessary to increase their independence and reduce their dependence on others.

Stated in terms of particular service requirements, this translates into six general classifications of services, of which residential services is only one.

1) Case Coordination Services -- Case coordination services include needs assessment, planning, service coordination, and follow-up services necessary to make the delivery system work well for clients.

2) Residential Services -- Residential services include the provision of food, clothing and shelter, the basic level of supervision necessary to insure the safety and well-being of clients, and the provision of training in self-care and community living skills. The residential services are divided into three subcategories for purposes of this needs assessment: residences providing high, moderate or minimal supervision;

3) Health Services -- Health services include services for evaluating the health status of individuals, for identifying and alleviating acute conditions, and for managing those chronic disabling conditions to the point where clients can function at the levels at which they would be able to function were it not for these conditions.

4) Educational and Vocational Services -- Educational and vocational services are designed to enhance the physical, communicative, social, affective and cognitive development of persons in order that they achieve and sustain the behaviors and skills necessary for them to maintain a lifestyle as culturally normative and as free of outside support as possible.

5) Client Support Services -- Special client support services include services designed to ameliorate chronic and disabling physical and behavioral conditions to the point where clients can function at the levels at which they would be able to function were it not for those conditions.

6) Caretaker Support Services -- Caretaker support services include the provision of those services that are necessary for residential, habilitative and health programs to work efficiently and effectively.

Thus, while this residential services plan concentrates on persons with developmental disabilities who cannot be expected to live independently (in unsupervised residential arrangements), it cannot and does not confine the scope of services needed to residential services alone.

Limitations of the Proposed Plan

The Institute is committed to the development of systems designed to offer services of the highest habilitative potential within least restrictive settings. Key to planning such services is reliable information pertaining to levels of functioning of present system clients, as well as those demanding, but not currently receiving, services.

As noted in previous technical reports, however, the data base currently available in New Mexico provides only partial information. Data gathered through COOP and the Institute's provider do not provide precise information on client functioning and service needs. Though certain types of information (e.g., client age) are no doubt accurate, other types (e.g., severity of disabling conditions) may not be as reliable. As a result, these data bases have limited utility for informing long term planning. For a more detailed discussion of data limitations, please review Section III of Part One of this report.

This is not to say that existing data on clients ought to be disregarded. Given the nature of strategic planning, the present data base does provide a useful, though limited, profile of the number and functioning levels of system clients. Recall that information on individual clients will not be used to devise personalized treatment plans. Rather, the client classification strategy employed is especially suited to assigning clients to seven broadly defined resource related groups. Available information was used to assign persons in the system to one of these groups. Overall, given inspection of the resulting distributions of clients across the seven planning groups, the classification system worked as intended.

Description of the Planning Framework

Over the past several years much has been done in New Mexico to establish a network of community services. Personnel, facilities and administrative practices are already in place to support the present system. The proposed residential services plan builds on this foundation and recommends the expansion and/or reconfiguration of some service elements. Obviously, each component of the plan cannot be set in motion at once. To be successful, system change must be attentive to the multiple complementary, and overlapping activities that must be coordinated and phased over the life of the plan. For instance, to proceed with residential expansion without moving simultaneously to improve quality assurance mechanisms would be ill-advised at best. To ensure that implementation of the plan occurs in a systematic fashion, the Institute suggests that a conceptual model be employed that takes into account present practices, specifies system objectives, sets procedures for achieving objectives, and times various tasks. Such a strategy will also ensure that implementation is both sound and efficient.

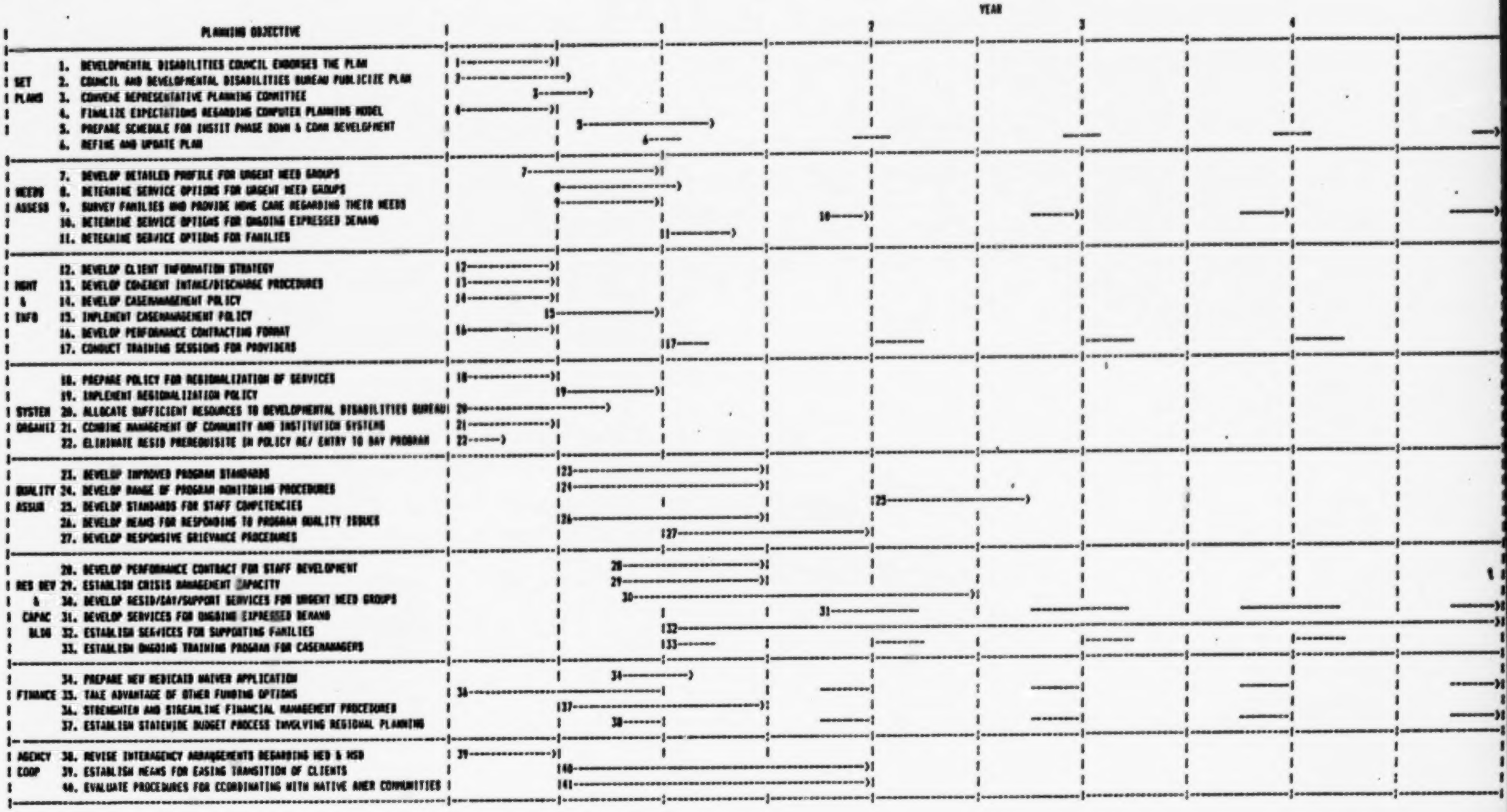
Figure 38 displays the conceptual model, lists proposed objectives and shows anticipated time lines. Primary components to the conceptual framework include:

- Categories of Proposed Objectives: Proposed objectives are assigned to one of eight general categories, each of which addresses a fundamental aspect of effective long term planning. These categories include: 1) planning, 2) needs assessment, 3) management and information, 4) system organization, 5) quality assurance, 6) resource development and capacity building, 7) finance, and 8) inter-agency cooperation;

- Timeframe for Plan Implementation: As noted above, it is important to coordinate the timing of all facets of the plan. Proposed activities are sequenced so that tasks of the highest priority and/or that are prerequisite to other objectives are undertaken first. Second and third order objectives follow in turn. To direct this sequenced process, the plan is set within a five year span, the first year involving objectives of the highest priority; and

- System Objectives: There are 40 planning objectives aimed at maintaining, reshaping or establishing a related policy or practice. Targeted objectives are listed within their appropriate category, allowing review of how various objectives are sequenced and fit together.

FIGURE 38



	PLANNING OBJECTIVE
SET PLANS	1. DEVELOPMENTAL DISABILITIES COUNCIL ENDORSES THE PLAN
	2. COUNCIL AND DEVELOPMENTAL DISABILITIES BUREAU PUBLICIZE PLAN
	3. CONVENE REPRESENTATIVE PLANNING COMMITTEE
	4. FINALIZE EXPECTATIONS REGARDING COMPUTER PLANNING MODEL
	5. PREPARE SCHEDULE FOR INSTIT PHASE DOWN & COMM DEVELOPMENT
	6. REFINE AND UPDATE PLAN
NEEDS ASSESS	7. DEVELOP DETAILED PROFILE FOR URGENT NEED GROUPS
	8. DETERMINE SERVICE OPTIONS FOR URGENT NEED GROUPS
	9. SURVEY FAMILIES AND PROVIDE HOME CARE REGARDING THEIR NEEDS
	10. DETERMINE SERVICE OPTIONS FOR ONGOING EXPRESSED DEMAND
	11. DETERMINE SERVICE OPTIONS FOR FAMILIES
MGMT & INFO	12. DEVELOP CLIENT INFORMATION STRATEGY
	13. DEVELOP COHERENT INTAKE/DISCHARGE PROCEDURES
	14. DEVELOP CASEMANAGEMENT POLICY
	15. IMPLEMENT CASEMANAGEMENT POLICY
	16. DEVELOP PERFORMANCE CONTRACTING FORMAT
	17. CONDUCT TRAINING SESSIONS FOR PROVIDERS
SYSTEM ORGANIZ	18. PREPARE POLICY FOR REGIONALIZATION OF SERVICES
	19. IMPLEMENT REGIONALIZATION POLICY
	20. ALLOCATE SUFFICIENT RESOURCES TO DEVELOPMENTAL DISABILITIES BUREAU
	21. COMBINE MANAGEMENT OF COMMUNITY AND INSTITUTION SYSTEMS
	22. ELIMINATE RESID PREREQUISITE IN POLICY RE/ ENTRY TO DAY PROGRAM
QUALITY ASSUR	23. DEVELOP IMPROVED PROGRAM STANDARDS
	24. DEVELOP RANGE OF PROGRAM MONITORING PROCEDURES
	25. DEVELOP STANDARDS FOR STAFF COMPETENCIES
	26. DEVELOP MEANS FOR RESPONDING TO PROGRAM QUALITY ISSUES
	27. DEVELOP RESPONSIVE GRIEVANCE PROCEDURES
RES DEV & CAPAC BLDG	28. DEVELOP PERFORMANCE CONTRACT FOR STAFF DEVELOPMENT
	29. ESTABLISH CRISIS MANAGEMENT CAPACITY
	30. DEVELOP RESID/DAY/SUPPORT SERVICES FOR URGENT NEED GROUPS
	31. DEVELOP SERVICES FOR ONGOING EXPRESSED DEMAND
	32. ESTABLISH SERVICES FOR SUPPORTING FAMILIES
	33. ESTABLISH ONGOING TRAINING PROGRAM FOR CASEMANAGERS
FINANCE	34. PREPARE NEW MEDICAID WAIVER APPLICATION
	35. TAKE ADVANTAGE OF OTHER FUNDING OPTIONS
	36. STRENGHTEN AND STREAMLINE FINANCIAL MANAGEMENT PROCEDURES
	37. ESTABLISH STATEWIDE BUDGET PROCESS INVOLVING REGIONAL PLANNING
AGENCY COOP	38. REVISE INTERAGENCY ARRANGEMENTS REGARDING MED & HSD
	39. ESTABLISH MEANS FOR EASING TRANSITION OF CLIENTS
	40. EVALUATE PROCEDURES FOR COORDINATING WITH NATIVE AMER COMMUNITIES

I. PLANNING

This system component encompasses all of those activities that are necessary to conceptualize and create plans for the conduct and development of the statewide developmental disabilities service system. It includes tasks directed at both the process of planning as well as aspects of comprehensive planning. In order to be successful, the process will require information and feedback from the other system components and should result in a time-table for resource development that is continually reviewed and updated. The following objectives should govern planning in the short run as well as over the next five years.

1. The Developmental Disabilities Council Should Endorse the Plan

Following the presentation of the HSRI Plan on April 11, the members of the Developmental Disabilities Council should review the recommendations for policy changes as well as programmatic shifts and determine whether an endorsement of the Plan is appropriate. Such an endorsement is important in order to provide momentum for the recommendations and to begin the process of building the consensus necessary to facilitate implementation. The endorsement should be sought as soon as possible so that the process of policy development and education can begin as soon as possible.

2. The Council and the Bureau of Developmental Disabilities Should Publicize the Plan and Disseminate the Document to All Relevant Constituencies

Following the endorsement of the Council, Council staff and staff of the Bureau of Developmental Disabilities should ensure that the results of the planning activity are circulated to all interested persons in the state including those who participated in the regional forums, the regional planning representatives, members of the Council of Providers, the Protection and Advocacy organization, state and local ARC chapters, state agency officials, legislators and staff, and any other relevant organizations.

As part of this process, it is suggested that presentations on the findings of the plan be made in each of the seven planning districts in order to answer questions and to begin to build support for the necessary programmatic and policy changes.

3. Convene a Representative Long Range Planning Committee

In order to assist the Council and the Bureau to build consensus regarding the content and direction of the plan and also to assist over the next five years in making "mid-course corrections," a long-range planning committee should be constituted. The committee should be broadly representative of the developmental disabilities community and should include advocates, consumers, legislators, state officials, and others with a direct interest in the shape and content of the developmental disabilities system.

While it is true that the Developmental Disabilities Council already has some of these responsibilities, it also has numerous other concerns and constituencies that would make it difficult to play a direct planning and advisory role. Some of the Council members, however, should clearly be on the newly constituted body in order to ensure continuity and coordination.

The responsibility of the committee in the first year should be as follows:

- Disseminate information concerning the planning process to relevant constituency organizations;
- Assist in the development of a detailed implementation schedule;
- Provide advice regarding agencies and individuals to be designated as responsible for particular aspects of the implementation plan;
- Serve as a conduit for feedback from the field regarding specific recommendations and directions;
- Assist in informing legislators regarding specific policy directions;
- Monitor implementation of plan.

4. Finalize Expectations Regarding the Computer Planning Model

HSRI, through its strategic planning model, will continue to work with the state following the submission of the Plan. Application of the computer-assisted model will yield more specific information regarding service packages tailored to client characteristics and will provide state policy-makers with more precise unit of cost figures. In order to ensure continuity between the plan and the application of the model, the following steps should be taken:

- Translate New Mexico client data into the model level-of-functioning categories (or vice-versa), translate New Mexico service data into model service categories, input estimates of service unit costs by type of service, and input the client population (demand) projections (within 60 days of Plan submission);
- Input plans of service by client level-of-functioning category and type of service (within 90 days of Plan submission);

- Project client outcomes and costs under alternative service strategies and funding constraints, and review and modify results through an iterative process involving key decision-makers and the planning committee until consensus is reached (within 180 days of Plan submission).

5. Prepare A Schedule for Institutional Phase-Down and Community Development

In order to guide the systemic and programmatic changes proposed in this Plan, a very precise schedule will be required. Such a schedule, which should be prepared by the Bureau of Developmental Disabilities with advice and input from the planning committee, should be developed in tandem with the needs assessment and resource development activities described below and should provide an important component to the new Title XIX waiver application developed under the financing component also described below.

The schedule should initially specify the pace at which the 127 residents of Fort Stanton and the 64 residents of Los Lunas under five years of age will be moved into alternative living arrangements, and the time involved in developing 135 community residential beds for those waiting for immediate residential placement. It is suggested that the schedule should reflect an approximately two and a half year to accomplish the anticipated movement.

Schedules should also be developed to govern subsequent resource development including the creation of more appropriate living arrangements for the 177 individuals currently listed as inappropriately placed in the community, and to meet projected demand over the next five years.

6. Refine and Update Plan

The aims of the plan and the steps required to carry it out should be continuously reviewed and updated by the Bureau of Developmental Disabilities in conjunction with the planning committee. Updates should be based on feedback from regional planning committees (see objectives 18 and 19 below), from the refined and expanded client information system, and from the reports of quality assurance monitoring (see objective 24).

As noted in the introduction to Part Two of the Plan, the data used for the preparation of the HSRI Plan are only partial and it will be important to use information generated from the data systems proposed below to refine and update expressed as well as latent demand figures.

Further, given the importance of ensuring the well-being of developmentally disabled clients served in the system, the plan and the implementation schedule should be continuously scrutinized to determine whether community capacity is being stretched too far too quickly.

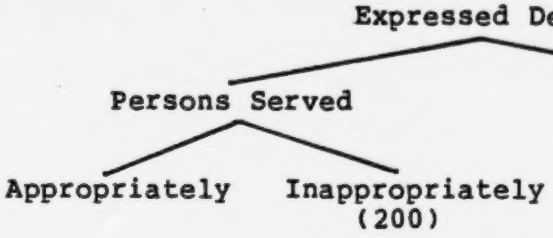
II. NEEDS ASSESSMENT

Needs assessment is an evaluation and planning activity designed to determine the service needs of some target population and what must be done in response. As noted in an earlier section, plans need not be made to serve all persons with developmental disabilities. Many of these persons function without public support (compensated demand) or will demand services only as additional habilitative options are made available (hidden demand). Others, however, are considered a higher priority because they are presently expressing a demand for service and are either served (appropriately or not) or on waiting lists (latent demand). Given these apparent demand categories, the Institute advises that New Mexico focus first on persons who are in urgent need of services. These persons are either served inappropriately at present or on waiting lists. Additionally, the Institute proposes that, with time, New Mexico focus on others without urgent needs who are already in the system or on waiting lists, and persons who are living at home.

7. Develop a Detailed Profile of Those Whose Service Needs Are Considered Urgent

Based on review of available information, the Institute concludes that some 400 persons have an "urgent" need for residential placement within community settings. As shown by Figure 39, these persons include those expressing a demand for service, but who are served inappropriately or on waiting lists.

Figure 39: 400 Persons whose Service Needs are Urgent



- 73 children aged 0-17 years presently in residence at Los Lunas;
- 127 persons presently in residence at Fort Stanton;
- 135 non-institutionalized persons on waiting lists for community settings presently living in situations judged to pose an immediate threat to their health or safety or unacceptably inadequate; and
- 65 non-institutionalized persons on the waiting list for placement in Los Lunas, nine of whom are under 5 years of age and 50 of whom are under 21 years old.

Key to matching these persons with an appropriate residence and level of supervision is information regarding their characteristics and functioning level. Consequently, the purpose of this objective is to secure a detailed profile of those assigned to this urgent need group.

Based on available information, Figure 40 shows the distribution by seven functioning level categories of the 400 persons in this highest priority target group. Note that the functioning levels of the 200 persons on waiting lists was not assessed directly, but was estimated based on capabilities of those already in community settings. Similarly, the functioning levels of the 73 children at Los Lunas was not assessed directly, but was estimated given the capabilities of the total Los Lunas population.

These initial findings suggest that persons in the target group generally have limited skills and that many have extraordinary disabling conditions. One may speculate that, with the exception of a sample of persons presently on waiting lists, these persons will require residential options offering high levels of supervision and access to a range of specialized services (e.g., physical therapy, behavior consultation).

Figure 40: Functioning Level of 400 Persons in Urgent Need of Residential Placement

FUNCTIONING LEVEL	THOSE AT FORT STANTON	CHILDREN AT LOS LUNAS	THOSE ON WAIT LISTS	TOTAL	PERCENT
1. SEVERE PHYSICAL/MEDICAL	18	31	7	56	14%
2. MODERATE PHYSICAL/MEDICAL	37	25	10	72	18%
3. ENDANGERING BEHAVIOR	3	2	9	14	4%
4. DISRUPTIVE BEHAVIOR	50	12	42	104	26%
5. MINIMAL SKILLS	15	3	29	47	12%
6. MODERATE SKILLS	2	0	71	73	18%
7. HIGH SKILLS	1	0	32	33	8%
UNKNOWN	1	0	0	1	0%
TOTAL	127	73	200	400	100%

These profiles, though instructive, are not sufficient for service planning purposes. The Institute recommends that additional effort be expended to obtain a more detailed profile of persons inthis target group than is available presently, especially regarding those on waiting lists. In part, needed information will be gathered during completion of Objective 12 (Develop Client Information Strategy), but in planning for appropriate community placement, care should be taken to profile these persons with regard to at least these four domains:

- Demographics: age, sex, county of original residence;
- Skill Level: capability of performing activities of daily living independently including self help skills (e.g., eating, toileting, dressing), basic living skills (e.g., preparing simple meals, combing one's hair, fixing one's bed), and advanced skills (e.g., going to the laundromat, regularly preparing balanced meals),

- Nature and Extent of Disabling Conditions: medical, physical or sensory complications, or the presence of problematic behavior; and

- Current Services Received: residential setting, day program, and specialized services.

The information collected need not be of exceptional detail. Information that focuses on specific skill domains is required to inform the development of individual program plans and should be collected by direct care staff as a matter of course. For planning purposes, however, these profiles are meant to assess overall levels of functioning and the extent of specific disabling conditions. This type of information is collected best through use of a standardized assessment measure of tested utility and psychometric credibility. Numerous such instruments exist. One measure developed recently and worth exploring is the Inventory for Client and Agency Planning (Bruininks, Hill, Weatherman & Woodcock, 1985). Information on this instrument is provided in an accompanying Appendix.

8. Determine Service Options for Persons Whose Service Needs Are Considered Urgent

The purpose of this objective is to determine the service options that must be made available to the 400 persons assigned to the urgent need group. In approaching this task, it is assumed that persons functioning at varying levels and of varying ages require differing types and amounts of services. For instance, young children with severe physical impairments who live in a foster home require services that are far different from those needed by adults with moderate adaptive skills who live in a community residence.

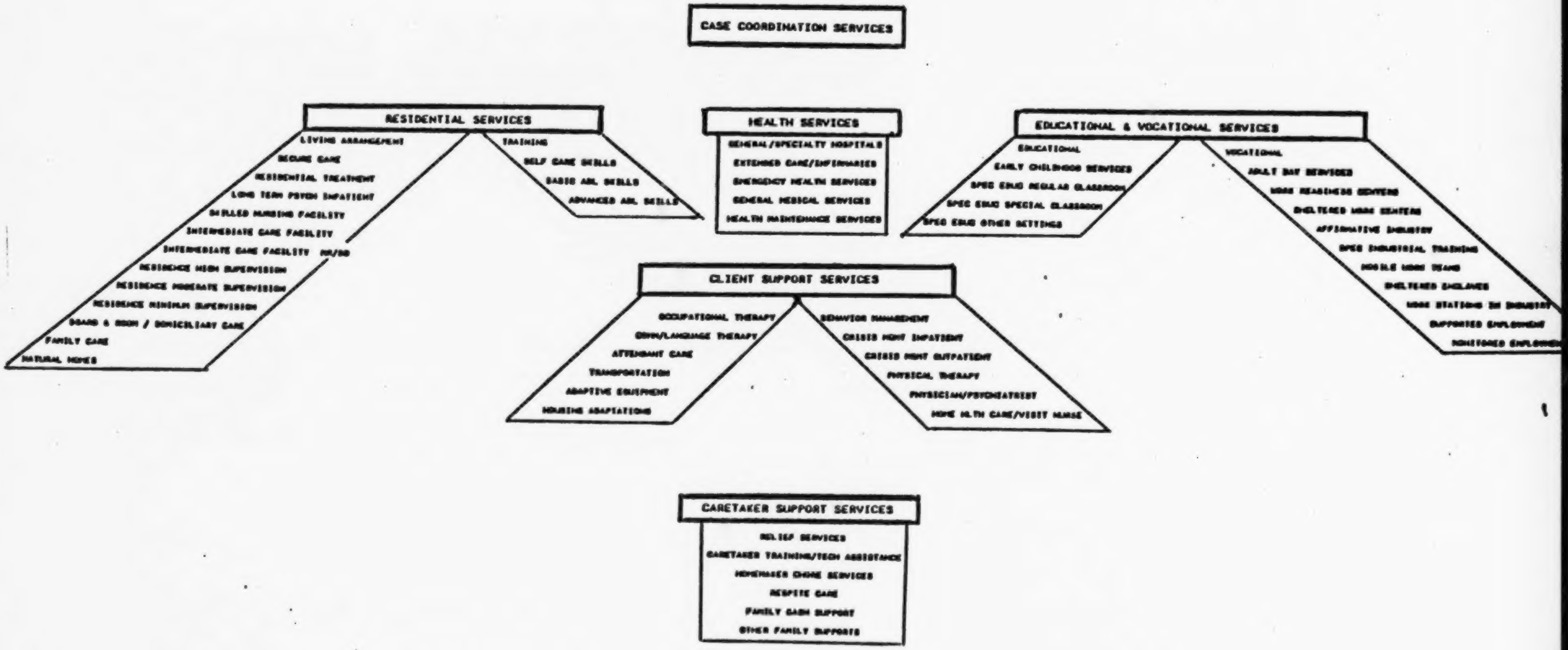
Figure 41 displays many of the services that could be required by persons with developmental disabilities living in community settings. Specific descriptions of these and other services are provided in an Appendix. As suggested by the variety of services displayed in this figure, concerned parties in New Mexico must reach consensus regarding what services types and amounts must be made available. The ensuing discussion will not always be easy, given a pressing need to expand the existing service continuum and natural tendencies to make use of already available models.

In developing service options for these 400 persons, however, the Institute offers these observational recommendations:

- Many of the 400 persons are young children. As a result, family like options, especially foster homes, should be vigorously pursued, even in cases where significant disabling conditions exist. Where foster placements are unavailable, small community residences of no more than six beds are preferred;
- Based on initial profiles (See Objective 7), many of the adults in this group will require high supervision. The traditional response to this need is the "group home." However, recent initiatives show that smaller highly supervised apartments are as effective, suggesting that available options should not be limited to the traditional group home concept;
- For those who function at high levels, moderate to minimally supervised settings (e.g., semi-independent living apartments) should not be overlooked;
- Given that a small number of persons in this target group may have exceptionally severe physical and/or medical impairments, certain settings may require the capacity for coping with life-threatening events. Thus, the Institute recommends that the state consider establishing no more than four additional six bed ICF-HR residences;
- As explained in Objective 34, plans for serving these 400 persons will be tied to the application for a new Home and Community Based Waiver (Medicaid funds). As a result, designing service options for this group should be undertaken along with efforts to prepare the application; and

FIGURE 41:

SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES



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- Developing a residential plan for these persons must also involve consideration of their day program and support service needs. For instance, given the number of children involved, public school officials must be encouraged to participate in the planning process. Likewise, given that many of these persons have complicating disabling conditions, steps must be taken to assure that staff are properly prepared (See Objective 28), and sufficient support and crisis management capabilities (See Objectives 29 and 30) are in place.

To promote needed discussion and consensus building, the Institute recommends that an "expert panel" be convened to review profiles of the 400 persons in this group and to determine what service options ought to be developed. The panel should be representative of all concerned parties and should offer the range of expertise needed to plan for this target group. Typically, the panel would include advocates, providers, institution representatives, service specialists (e.g., behavior consultant, nurse), public school representatives, and state officials. Led by a facilitator, knowledgeable of contemporary service approaches, panel meetings would provide a forum for airing contrasting views, solving problems, and forging a common interest in developing the needed range of services.

9. Survey Families Who Provide Home Care to Persons with Developmental Disabilities

In New Mexico, the great majority of persons with developmental disabilities live at home with their families. The presence of a person with developmental disabilities in the home can present the family with a variety of extraordinary challenges. For many families the initial recognition that a severe disability exists in a child presents an immediate crisis that evolves into a life crisis. Available research suggests that the problems experienced by individual families are related to multiple factors including the seriousness of the family member's disability, the presence of maladaptive behavior, family characteristics, specific parenting patterns, the family's capacity for coping with adversity, and the availability of community support services. As a result, several analysts note that though not all of these families have extraordinary problems, all are "at risk" because they are more likely to have difficulties than families without members with disabilities. With few exceptions, however, these families receive no services to enhance their capacity to provide care or to deter unnecessary out-of-home placements.

Moreover, many families faced with extraordinary expenses incurred while caring for a child with exceptional handicapping conditions are often left with little choice but to place their child out-of-home. Consider that the present eligibility criteria associated with Medicaid creates a perverse disincentive to home care. When applying for Medicaid, until a child is 18 years old, the parents' income is counted as an asset of the child, leaving many children with parents of moderate income and above ineligible. In contrast, if the child is placed in an institution, parental income is no longer considered at his/her disposal and the child likely is found eligible for Medicaid. Thus, faced with extraordinary medical costs, families are often forced to place their child out-of-home. In New Mexico, only the Medicaid Community-based Waiver program offers a means for families to bypass problematic eligibility criteria. The Waiver program, however, has fallen short of expectations, serving relatively few persons. In part, these conditions may explain the high numbers of children with severe handicapping conditions under 21 years old at Los Lunas (n=113 with eight under five years old) and on its waiting list (n=50).

In many respects, the conditions described above are not atypical. Until 1980, few states were concerned with supporting families. Since 1980, however, numerous states have made developing state-wide family support programs a high priority. Often, programs are initiated as small pilots, growing in size with time. Though programs in most states are embryonic and fragile enterprises, serving relatively few families, the real and potential benefits have not gone unnoticed. Given a comprehensive array of supports:

- The family benefits because of an enhanced capacity to provide care and an improved quality of life. Moreover, for some parents, receiving support services obviates any need for seeking alternative placement for their child or makes it possible for them to bring their child home from such placements;
- The person with developmental disabilities benefits because he or she is able to stay in a supportive home with more capable caregivers; and
- The state benefits because it has strengthened the family structure and may realize some cost savings due to a diminished need to fund expensive alternative residential options.

In this light, the Institute advises that plans be made for developing a family support program for New Mexico (See Objectives 11 and 32). To inform the establishment of this program, the conduct of a family needs survey is warranted. At the least, the Institute recommends that a stratified sample of caregiving families be drawn and that they be sent a mail survey covering such topics as: 1) family characteristics, 2) the characteristics of the family member with disabilities, 3) family needs, 4) current services received by the family, 5) family satisfaction with current services, and 6) planned placement preferences. Complemented with the knowledge and experiences of eprsons in New Mexico familiar with family needs, information gathered through this survey could be used to inform the planning process, educate decision makers around the state and spur widespread support for a family support initiative.

10. Determine Service Options To Accommodate Ongoing Expressed Demand

Though planning for persons whose needs are considered is a high priority, the Institute recognizes that much must be done to reshape existing service structures to make them more responsive to currentclients and to meet the needs of those who will require services in the near future. The purpose of this objective is to set in motion a long term planning initiative which, over five years, will shape the service system to reflect contemporary practice and the preferences of persons in New Mexico.

As shown in Figure 42, aside from the 400 persons considered in urgent need (See Objective 7), there are 1,015 persons whose needs must be met, including:

- 274 persons at Los Lunas, many of whom are under age 21 and have severe handicapping conditions. The Institute recommends that with time these persons be placed in community settings. In the meantime, the recent federal "look behind" survey strongly reinforces the need to improve the level of care for those who remain at Los Lunas;
- 177 non-institutionalized persons on waiting lists for community settings; and
- 564 persons presently receiving community residential services, some of whom are placed inappropriately. (Note: an unknown number of the 177 on waiting lists may also be included in this figure).

Based on information collected during the project, Figure 42 shows these persons by seven functioning levels. Again, because functioning levels of those on waiting lists could not be assessed directly, the distribution of persons already in community settings was used to assign persons on waiting lists to a functioning level.

Figure 42: Functioning Level of 1,015 Persons Requiring Residential Services

FUNCTIONING LEVEL	PERSONS AT LOS LUNAS	PERSONS IN COMMUNITY SETTINGS	PERSONS ON WAIT LISTS	TOTAL	PERCENT
1. SEVERE MEDICAL/PHYSICAL	117	18	6	141	14%
2. MODERATE MEDICAL/PHYSIC	94	26	9	129	13%
3. ENDANGERING BEHAVIOR	6	22	8	36	4%
4. DISRUPTIVE BEHAVIOR	44	108	37	189	19%
5. MINIMAL SKILLS	13	74	26	113	11%
6. MODERATE SKILLS	0	184	63	247	24%
7. HIGH SKILLS	0	80	28	108	11%
UNKNOWN	0	52*	0	52	5%
TOTAL	274	564	177	1015	100%

* THE FUNCTIONING LEVEL OF 52 PERSONS IN DISTRICT 3 IS UNKNOWN

These findings show that, excepting the endangering behavior category, significant numbers of persons are found at each level and suggest that to provide appropriate residential care, an array of options must be available.

Figure 43 displays the 564 persons living in community residences by type of service and planning district. Note that the three columns depicting residences of varying levels of supervision actually are "group residences." They are set off from the group residence category because five of the districts furnished information on the level of supervision provided in their group homes.

Figure 43: Persons Receiving Residential Services in New Mexico by Type and Planning District

DISTRICT	ICF-MR	GROUP RESIDENCE	RESIDENCE HIGH SUPERV	RESIDENCE MODERATE SUPERV	RESIDENCE MINIMAL SUPERV	COMPANION HOMES	FOSTER HOMES	TOTAL
1	--	59	--	--	--	--	--	59
2	--	80	--	--	--	--	--	80
3	71	4	--	68	52	35	--	230
4	--	32	--	--	31	--	7	70
5	--	22	--	--	--	--	--	22
6	10	36	33	12	--	--	--	91
7	--	--	12	--	--	--	--	12
TOTAL	81	233	45	80	83	35	7	564

This figure suggests that the primary community residential option is the group residence, 441 of 564 (78.2%) live in such programs. Additionally, two districts operate ICF-MR's that serve 81 persons, one offers companion homes for 35 persons, and one offers a foster home placement for seven persons.

Figure 43 also shows that the great majority of persons are placed in District 3 (n=234 or 40.8% of those in community services), while District 7 (n=12) and District 5 (n=22) serve the fewest. These findings are not surprising given the distribution of the state population. Figure 44 displays presents a percent comparison by planning district of the state's population distribution and distribution of those in varying community options. As shown, five of seven districts come close to matching their percentage of the state population. However, District 7 appears to serve a significantly lower percentage than expected, while District 4 serves a greater share.

Figure 44: Percent Comparison of Population and Community Residential Service Distribution by Planning District

PERCENT OF	PLANNING DISTRICT 1	2	3	4	5	6	7	TOTALS PERCENT ALL DIST	TOTALS NUMBER ALL DIST
STATE POPULATION	10.9%	13.8%	39.1%	5.8%	3.7%	17.1%	9.6%	100%	1,462,984
THOSE IN RESID SERVICE	10.5%	14.2%	40.8%	12.4%	3.9%	16.1%	2.1%	100%	564

Viewed still another way, Figure 45 presents the percent of the 564 persons living in community residences in each district by functioning level. As shown, clients are not distributed evenly across districts by functioning level. Some districts seem to serve disproportionate shares of persons at certain functioning levels. For instance, perhaps owing to the presence of ICF-HR residences, districts 3 and 6 serve higher shares of persons with severe medical/physical impairments. It should be noted, however, that districts 1 and 2 serve similar clients, primarily in group residences. Similarly, District 4 serves an unexpected high proportion of persons with high skills (43.3% of 70 persons) compared to the overall statewide distribution (15.6% of 564 persons). Finally, District 3 seems to serve a disproportionate number of persons with disruptive behavior (34.3% of 230 persons) in comparison to the statewide share (21.1% of 564 persons).

Figure 45: Types of Persons Receiving Community Residential Services By Planning Districts

CLIENT FUNCTIONING LEVEL	PLANNING DISTRICT 1	2	3	4	5	6	7	TOTALS PERCENT ALL DIST	TOTALS NUMBER ALL DIST
SEVERE MEDICAL/PHYSICAL	0.0%	5.0%	5.0%	0.0%	0.0%	5.5%	0.0%	3.5%	18
MODERATE MEDICAL/PHYSICAL	5.1%	7.5%	6.2%	0.1%	4.5%	4.4%	0.0%	5.1%	26
ENDANGERING BEHAVIOR	8.4%	5.0%	3.4%	0.1%	0.0%	6.6%	0.0%	4.3%	22
DISRUPTIVE BEHAVIOR	27.2%	13.7%	34.3%	4.3%	4.5%	16.5%	8.3%	21.1%	108
MINIMUM SKILLS	15.3%	25.0%	14.6%	7.1%	4.5%	13.2%	8.3%	14.5%	74
MODERATE SKILLS	27.2%	25.0%	33.1%	43.3%	50.0%	41.7%	83.4%	35.9%	184
HIGH SKILLS	16.9%	18.3%	3.4%	43.3%	36.5%	12.1%	0.0%	15.6%	80
UNKNOWN	--	--	--	--	--	--	--	--	52
TOTAL PERCENT	100%	100%	100%	100%	100%	100%	100%	100%	--
NUMBER PER DISTRICT	59	80	230*	70	22	91	12	--	564

* THE FUNCTIONING LEVELS OF 52 OF THESE CLIENTS IS UNKNOWN.

Overall, in reviewing Figures 42 - 45, the Institute offers the following observations and recommendations:

- Though the present community system offers a sound base from which to build, the existing continuum ought to be expanded. Numerous persons functioning at the highest skill levels could benefit from less restrictive residences than the group home. Examples include semi-independent living residences, supervised apartments, and board and care residences. Likewise, in anticipation of accommodating persons with the severest disabilities in the community, steps must be taken that the level of care required will be available;

- By our count, New Mexico currently has 191 clients in high supervision residential arrangements in the community -- 124 in ICF/MRs and 67 in group homes. We estimate that 48 of these clients (those with disruptive behaviors and those with moderate to high skill levels) could benefit from moderately supervised arrangements, freeing up beds for persons with more severe handicaps;

- Due to an absence of appropriate community residential options for persons with severe medical or physical disabilities, some of these persons live in nursing homes. Alternative options within less restrictive settings ought to be explored. Over time, to the extent feasible, these persons should be assigned to residences that are integrated more fully into the community;

- To date, the development of community services has generally matched state population distributions by district. In moving to expand services, care must be taken not to upset this balance. Owing to the availability of specialized services in populous areas, tendencies to concentrate residences for persons with exceptional disabilities may grow strong. In some instances this may be unavoidable, since it may be best to concentrate resources for particular services in few areas. However, plans to build the service capacity of rural areas should be pursued;

- In expanding the residential continuum, complementing day programs must also be addressed. Certainly, more day program slots will be needed, given that only 23% of adults living in the community receive day services and in anticipation of persons graduating from public schools. Additionally, the types of day programs available must be expanded. The state should rely on segregated facilities (e.g., sheltered workshops, activity centers) and more on integrated options (e.g., affirmative industry, sheltered enclaves, supported employment); and

- The need to build needed client, staff, and administrative supports into expansion of direct care capabilities ought to be a high priority. Indeed, numerous other objectives of this plan focus on this end.

Over the course of this five year plan, a determination on which service options must be established to accommodate the ongoing expressed demand must be made. Certainly, divergent interests will emerge as abstract concepts such as "least restrictive alternative" and "community integration" are operationalized. To promote such needed discussion and provide concerned parties with a systematic means for building consensus, the Institute recommends that an "expert panel" be convened to determine the needed service options. This panel may be separate from the one proposed in Objective 7 or be composed of many of the same persons. Working with the representative planning committees (Objective 3), this panel will be charged with meeting regularly to advise the state of the service options that must be put in place to expand and enhance present service structures.

11. Develop Service Options for Families

In light of information gathered through completion of Objective 9, the purpose of this objective is to determine what service options will be made available over the next five years to families who provide home care.

No two persons with developmental disabilities or two families are alike. Considerable variation exists regarding disability types and severity, family characteristics and resources, and family perceptions of the caregiving situation. Moreover, these factors are not static but evolve over time.

These considerations suggest that besides the direct care services persons with disabilities receive outside the home, responsive support programs must permit a wide array of services and encourage each family to select those services that are most appropriate for its needs. Figure 46 displays the numerous services families and their members could require. The list was distilled from a review of existing family support programs operating around the country and suggests that in addition to the direct care services required by the family member with disabilities, the family also needs support services to enhance its caregiving capacity.

FIGURE 46: List of Services Required by Persons with Developmental Disabilities and Their Families.

Home-Based Services Centered Around the Person with Disabilities	Services Centered Around Family Members
adaptive equipment	information and referral
educational/therapeutic services	temporary relief/respite
transportation	family counseling
medical or dental services	parent/sibling education
home barrier removal	homemakers
special clothing	chore services
special diets	housekeepers
diagnosis and assessment	cash assistance
medication	future financial planning
home health care	
attendant care	
recreational services	

These potential service needs are not ranked in order of importance. Each family has a unique cluster of needs and would place a different value on each service depending on their immediate circumstances; some may require few services, while others may need many. Additionally, many families may have needs that do not appear on the above list.

In determining what options should be made available and how a family support program ought to be administered, the Institute advises that the state attend to the preferences of family members. Their preferences, complemented with the knowledge and experiences of professionals in the state, should be used to design the state's first comprehensive family support program.

Like other states, New Mexico may benefit from piloting a model of the program with a few families (less than 50) to gain experience and make adjustments to the program. With time, however, the program ought to be expanded systematically until it is available statewide.

III. MANAGEMENT AND INFORMATION

This system component encompasses those activities necessary to operate and administer a system of services for persons with developmental disabilities. It includes the organization of information systems, the development of viable administrative and planning structures, as well as the creation of uniform intake and discharge procedures. The elements of this component are crucial to the maintenance of an equitable system of services as well as one that is responsive to the state's priorities and needs.

12. Develop A Client Information Strategy

Staff of the Developmental Disabilities Bureau should immediately establish a system of annual assessments of active clients and residential and day service applicants to be used as a basis for assessing program needs and requirements. The information should be sufficient to assess the adequacy and appropriateness of their current residential/day service level, and the urgency of need for alternative placements. The assessment should be made an integral part of the individual planning process.

The current COOP data base provides adequate information on client demographics and services received, but does not include information necessary to develop a valid picture of the individual's level of functioning. The only indicators currently available are based on gross categories derived from I.Q. scores. To generate client information in a standardized fashion, it is suggested that an existing instrument already established in the such field, such as the Inventory for Client and Agency Planning (ICAP) developed at the University of Minnesota (See accompanying Appendix). An important benefit of using a pre-existing instrument is the ability to compare the characteristics of New Mexico clients with national norms.

It is strongly suggested that the selection of any assessment tool be done in conjunction with the planning committee and a special task group comprised of providers from around the state. Such consultation should help to insure the acceptability and utility of any instrument selected. It is also recommended that the current COOP instrument serve as the core of any new assessment form to ensure continuity of data collection. All providers, including ICF/MRs, should be required to supply assessment information as a requirement of state funding.

With the development of a comprehensive client assessment process, state developmental disabilities officials will be in a position to establish eligibility criteria based on a system of priority rankings that can be used at intake into all developmental disabilities services including ICF/MRs. Such rankings can also be used to structure a statewide waiting list ordered according to urgency of need. Further, to improve the quality and coverage of the current waiting list, a more concerted effort should be made to solicit applications through advocacy as well as provider organizations from individuals with an express demand for services. Only with the information provided through these annual client assessments and the mandatory wait-listing requirement can New Mexico have sufficient information and control to bring about a balanced system of residential/day services responsive to the full range of service requirements.

13. Develop Coherent Intake and Discharge Procedures

One of the problems in managing the current system of services is the lack of any consistent, coherent and centralized policy governing the admission of clients into services or the discharge of individuals with developmental disabilities out of residential and day services. In the case of ICF/MRs, the intake and discharge process functions even more independently of the Bureau of Developmental Disabilities than in the non-Medicaid-funded system.

A great deal of attention has been paid during the past several months to the development of regulations to govern admissions to residential services of individuals who are not capable of giving their consent. The most recent proposal put forward by the Developmental Disabilities Bureau would require that such individuals be given a guardian to consent to services on their behalf. While the issues of due process and consent to services are clearly important, their resolution will only partially solve the problem addressed in this objective -- the lack of a recognized entry point into the system and control over movement and discharge of clients based on individual needs and system priorities.

Control over admissions and discharges of persons with developmental disabilities to and from all state-funded services, including ICF/MRs, should be vested in a regional case management system fielded by the Bureau of Developmental Disabilities (see Objectives 14, 15, 18, and 19). Admission and discharge decisions should be made on the basis of the uniform client assessment tool described in Objective 12 and should be governed by regional and statewide priorities as well as the urgency of need. The centralization of admission decisions will ensure that those most in need receive services and that individuals receive services appropriate to their needs. Centralizing discharge review will make it possible to investigate requests to move clients who are felt to be too disruptive by providers and to develop alternative means of supporting the provider and the client where feasible (see Objective 29 for a discussion of crisis management capabilities).

The development of a more systematic and coherent intake policy is also important to the successful implementation of the Medicaid waiver in the state. In a recent assessment of the New Mexico waiver experience, Brian Burwell of Systemetrics (1985) commented on the fragmentation between HSD and HED and strongly recommended that intake and eligibility determinations be simplified and unified. Burwell noted that implementation of the waiver should not be a separate and parallel activity but rather "should be designed in conjunction with efforts to implement more centralized management over the delivery of community-based services to the developmentally disabled in New Mexico."

14. Develop a Case Management Policy

One of the key ingredients necessary to ensure a responsive system of community services is a case management capability. Further, for case management to be client-centered and free of bias, it should be independent of providers of direct services whenever possible. In some states, such as Colorado, case managers are employed by the same agency at the local level that provides direct services. In California, case management is performed by a regional center that is totally separate from direct service providers. With the exception of the small case management capacity developed as a result of the Medicaid waiver in the state, case management has yet to become a formal part of New Mexico's community system for developmentally disabled persons. It is therefore possible to create a case management system that has no previous affiliations or allegiances.

It is recommended that case managers be employed by the Developmental Disabilities Bureau and located in regional offices in the seven planning regions in the state (see Objective 18). Case managers should be responsible for all clients including individuals in institutions, ICF/MRs, waivered services and other state-funded arrangements. Specific responsibilities should include:

- Screening all clients applying for services and maintaining the waiting list;
- Working with a multi-disciplinary team that includes the client and his or her family to develop an individualized program plan;
- Ensuring that initial and annual assessments are carried out on each client;
- Monitoring service plans to determine whether appropriate services are being provided;
- Monitoring residential arrangements and day program placements to ensure client well-being.
- Supervising the transition of institutional residents into community placements.

The importance of a case management system is also underscored by Burwell in his waiver assessment.

> Further development of a case management infrastructure within the DD Bureau would be another important factor in the new waiver program. Ideally this case management system would encompass not only activities relating to the waiver program itself, but would be closely linked to admission and discharge planning in public and private ICF/MRs. For example, the system should be able to identify persons who are currently residing in public or private ICF/MRs who could be served more appropriately, and at less cost, under the waiver, as well as persons on waiting lists who could be diverted. (p. 26)

The importance of case management in the development of a mature community service system that takes responsibilities for persons with serious disabilities is underscored in the five year study of the deinstitutionalization of mentally retarded individuals from Pennhurst Center in Pennsylvania (Conroy & Bradley, 1985). The study also commented on caseload size:

> . . .case managaement is a critical function in any community service system. In the Pennhurst case, Judge Broderick issued an order that 30 case managers be hired and assigned to service about 900 people, resulting in caseloads averaging 30. The quantitative data hint, and our years of discussions with knowledgable key actors strongly suggest, that case managers must have sensible caseloads to be functional at all. (p. 346)

The Bureau of Developmental Disabilities in conjunction with the planning committee should immediately formulate a policy on case management in the state that includes a job description, a target caseload size, salary ranges, and training requirements. The policy should be integrated into the waiver request and promulgated at part of the state's regulations. Consideration should be given to including the policy formally in the Developmental Disabilities Act.

15. Implement a Case Management Policy

Following the promulgation of a case management policy in the state, a schedule of implementation should be developed including a plan for phasing in case managers in the seven regions, a strategy for recruitment, and a statement of priorities regarding those most in need of immediate case management. Implementation of the case management system should occur in tandem with the development of regionalization and the creation of an improved client information system.

16. Develop a Performance Contracting Format

The changes recommended in this plan will require a clear understanding on the part of all system actors regarding future system directions and the relative roles to be played by the state and the providers of community services. One way of ensuring that expectations are made explicit is through the design of a mutual performance contract between the Developmental Disabilities Bureau and service providers. Some of the specific provider responsibilities embodied in such a contract could include the following:

- the nature of the client group to be served;
- the values (e.g., integration, individualization) and policies that should govern service delivery;
- the specific services to be delivered.

Some of the state's responsibilities should include:

- support for technical assistance and crisis management;
- case management and individual client assessment;
- analysis of client and service data and presentation of results in a relevant and timely format;
- provision of adequate financial support.

The terms of the mutual performance contract with each provider can be renegotiated each year to encompass changes in the state of art and in state and regional priorities.

17. Conduct Training Sessions for Providers

To inform providers and to generate feedback regarding improved client assessments, revised intake and discharge policies, and case management systems, the Developmental Disabilities Bureau should conduct training sessions for providers in the seven planning regions.

IV. SYSTEM ORGANIZATION

This system component is concerned with the way in which the service system must be designed to accomplish the anticipated reforms. It includes activities aimed at developing a regionally-based planning and case management structure as well as objectives directed at the organization of the state Developmental Disabilities Bureau and the allocation of responsibilities within the Health and Environment Department.

18. Prepare A Policy for the Regionalization of Services

The current system of services for persons with developmental disabilities in New Mexico has no intermediate or mediating entity between those who provide services at the local level and those who fund and regulate services at the state level. In many other states, this role is played by county government (Pennsylvania and Minnesota), a state regional office (Illinois and Massachusetts), or an independent provider agency (California and New Hampshire).

The rational for the creation of a regional structure is multifold. First, it provides a locus for planning and facilitates the expression of planning priorities and needs from a variety of constituencies including families, advocates, consumers, and local citizens as well as provider agencies. Second, a regional mechanism can also serve a monitoring function and can provide a vehicle for expressing grievances and lodging complaints. Third, a sub-state system affords an appropriate location for case management and individual program planning. Fourth, it can serve as a point of coordination with other agencies on behalf of clients with disabilities. Fifth, it can assist local providers to coordinate their efforts and to develop mutual goals and expectations regarding services region-wide. Sixth, and finally, a sub-state structure will make the management of community-based serivces more responsive as the system continues to grow over the next five to ten years.

HSRI strongly recommends that, for all of these reasons, New Mexico develop a regional system of services and that a policy be developed by the Developmental Disabilities Bureau in consultation with the planning committee that calls for the development of widely representative planning committees in each region. Planning committees should be responsible for garnering input regarding needs in the region on an annual basis and should also be vested with a monitoring responsibility (see Objective 24). Plans for regionalization should also include the development of a case management capability. (see Objective 14 and 15 above).

The policy should also address the optimum number of planning regions. This will involve a review of the current seven regions to determine whether they represent rational groupings, taking into consideration local culture, level of service development, nature of service need, and service area. Since the development of sub-state entities is a major addition to the system, state officials should include as much public input into the development of this policy as possible.

19. Implement Regional Policy

It is understood that financial constraints may delay the immediate implementation of all facets of a regionalized system. However, that part of the regional policy concerned with the creation of regional planning bodies could be established quickly since planning board members would be serving as volunteers. Travel and other organizational costs could be initially covered by the Developmental Disabilities Council until permanent line items can be secured in the budget. Organizational meetings could include orientation sessions regarding the contents of the residential plan and training regarding program monitoring.

To a large extent, the process devised by the Developmental Disabilities Council to govern the preparation of the residential plan (i.e., regional forums and inclusion of regional planning representatives in the review of subsequent iterations of the plan) provides a foundation for the formalization of regional planning entities.

20. Allocate Sufficient Resources to the Developmental Disabilities Bureau for the Management of the System

The system of services for persons with developmental disabilities in New Mexico has expanded and matured over the past several years. However, the ability of state developmental disabilities officials to manage and oversee the system have clearly not kept pace with this growth. This problem has become more apparent as the experience with the Title XIX community-based waiver has come under recent scrutiny. Burwell, in commenting on the state's capacity to manage the waiver, made the following observation:

> Upper-level management at HED has apparently not recognized the long-range potential of the Medicaid waiver as a financing source for community-based service development. It has not made adequate resources available to implement and manage the waiver program effectively. (p. 2)

In addition to management of the waiver, the Bureau also will need resources to manage and interpret an improved client information system (see Objective 12), to administer a comprehensive quality assurance system (see Objectives 23 to 27), and to anticipate the need for training and technical assistance resources (See Objectives 28, 29, and 33). It is understood that the state is facing serious revenue short-falls and that additional funds to support an expanded Bureau may not be easy to secure. However, if such resources are not made available soon, the state risks losing waiver dollars as well as many of the community system gains that have been made in the past few years.

21. Combine the Management of Community and Institutional Services

The conduct of state-run and community-based services are inextricably linked. The separation of the administration of institutional services from community services at the state level goes against all rational notions of system organization in the field of developmental disabilities. Such a separation creates a serious handicap to any form of comprehensive planning and system develop and makes efficient management and decision-making very difficult. It is strongly recommended that this bifurcation of responsibility cease immediately and that oversight of institutional programs be returned to the Developmental Disabilities Bureau.

22. Eliminate the Need for Residential Placement To Secure Day Services

During the course of key informant interviews, HSRI staff were told by parents that to secure admission to a day program in New Mexico, they were forced to place their family member out of the home since individuals living at home are not considered eligible for day programs. These family members noted that some of those on the waiting list for residential services may in fact be individuals who fact need a day program and whose families are willing to keep them at home. If admission to day programs is in fact limited to residents of group homes, this policy should be altered and individuals living with their families should be allowed entry on a phased basis. Further, individuals on the waiting list should be surveyed determine whether a day program alone would meet the needs of the family member with developmental disabilities.

V. QUALITY ASSURANCE

Quality assurance is another key component in a comprehensive service system for developmentally disabled persons. It is an element that, in many states, has been inadequately developed and unevenly applied. In too many instances, quality assurance resources have been cut back at a time when community programs are expanding which in turn has significantly handicapped program oversight. Quality assurance systems, to be successful must satisfy several objectives, including to ensure that: 1) services are provided consistent with accepted professional practice; 2) providers have the capacity to provide an acceptable level of services; 3) that a commitment of resources produces a reasonable level of service; 4) that services provided have the intended effect; and 5) that services are provided to those most in need.

The major ingredients of a quality assurance system are standards, monitoring systems, and control and enhancement activities. To be successful, quality assurance mechanisms must both regulate as well as enhance service quality.

23. Develop Improved Program Standards

A major vehicle for the communication of program aspirations is a set of program standards that delineate optimum service approaches. The changes envisioned in this plan will require significant alterations in service approaches over time and therefore will be greatly facilitated by the development of model program standards for both residential and day services. It is strongly recommended that the Developmental Disabilities

Bureau in consultation with the planning committee and the Developmental Disabilities Council develop standards that will exhort the current system to higher levels of achievment and that are reflective of emerging concepts in the field of developmental disabilities. Specifically, such standards should address individualized planning, functional learning principles, techniques of community integration, non-aversive means for coping with client behavior problems, client privacy and regimentation issues, client participation in decisions about his or her well-being, supported work and other important service concepts. Finally, standards should address requirements regarding accessibility of residential as well as day programs.

Standards should be divided into two parts -- threshold or minimum standards that all providers should meet in order to remain in operation, and model or optimum standards that can serve as the aspirations or ultimate goals for providers in particular and for the system in general. Model standards should continually updated to reflect the state-of-the art. In this way, they can constantly serve as challenge to the system.

Many states and agencies have developed standards that could be adapted for use in New Mexico. The two major accreditation agencies -- the Council for the Accreditation of Rehabilitation Facilities (CARF) and the Accreditation Council for Services to Mentally Retarded and Other Developmentally Disabled Persons (AC-MR/DD) -- can also be used as a guide. Thus, there is no need to struggle with the task of creating a wholly new set of standards.

24. Develop a Range of Program Monitoring Mechanisms

The development of minimum and optimum standards are only a first step in the development of a viable quality assurance system. Once standards have been developed, mechanisms must be developed to ensure that standards are being met. HSRI recommends that several monitoring activities be initiated -- each with a specific purpose and intent:

- At the regional level, citizen and family monitoring teams should be recruited and trained to conduct site visits to residential and day programs. The use of volunteer monitors has proved successful in many parts of the country including in Ohio and at the Macomb-Oakland program in Michigan.
- Regional case managers should be responsible for monitoring the implementation of individual client program plans to determine whether services are being provided and whether the interventions are effective;
- The client assessment data (see Objective 12) should be reviewed periodically to determine whether clients are gaining, maintaining, or decreasing in skill levels;
- An independent third party should conduct period program reviews to assess progress toward optimal service standards. Such reviews can be conducted by an outside contractor or a national accreditation organization.
- State staff should review programs yearly to determine compliance with minimum standards.

25. Develop Standards for Staff Competencies

To accompany an improved program monitoring system, the state should also consider phasing in a process for certifying the competence of direct care staff in both the institutions as well as in the community programs. The basis for the certification should include training in first aid and CPR, behavior management techniques, principles of normalization and community integration, as well as other skills deemed necessary to supervise and care persons with developmental disabilities.

26. Develop a Means for Responding to Program Quality Issues

As noted earlier, a major component of any quality assurance system should be control and enhancement activities. In other words, the system should have the capacity to respond to problems uncovered as a result of quality assurance monitoring. In most state systems, the major response is negative and usually involves closure or the requirement of a plan of correction and a probationary period. While these responses must clearly be developed and available to state program regulators, the option of providing assistance and support should also be present.

In the section on resource development and capacity building, we discuss the creation of a staff development contract and a crisis management entity (Objectives 28 and 29). These two resources should be used to support agencies where problems in quality have been uncovered by citizen monitors, state surveyors, case managers or outside reviewers.

27. Develop Responsive Grievance Procedures

Another way of ensuring that services are adequately provided and that clients' rights are protected is to create a grievance mechanism that can be used by consumers, their families and their advocates. To be responsive, the grievance mechanism should be independent of the provision of services. HSRI recommends that in New Mexico, the responsibility for reviewing grievances should initially fall to the newly-formed regional planning groups. Such bodies can serve as hearing boards for the purpose of investigating complaints and making determinations regarding appropriate actions. Appeals to decisions at this level can be made to the Developmental Disabilities Bureau.

Several states have developed comprehensive grievance mechanisms that can be reviewed for applicability in New Mexico. Specifically, we would suggest looking at the regulations governing the system in the state of New Hampshire.

VI. RESOURCE DEVELOPMENT AND CAPACITY BUILDING

A primary goal of the service system is to provide superior habilitative care and to assure a decent quality of life for its clients. In great part, achieving this goal is dependent on more than simply furnishing needed direct client services. Additionally, services in support of caretakers must also be available to assure that staff are properly prepared to teach needed skills, carry out essential routines and cope with crisis events. As these systems are set in motion, plans to increase the system's capacity to provide direct care may proceed with greater confidence.

28. Develop a Performance Contract for Staff Development.

Key to the success of any service system for persons with developmental disabilities is the recruitment, retention and development of competent staff. The importance of well trained staff for promoting client skill acquistion while fostering a safe and nurturing environment is well documented. Moreover, systems that retain competent staff generally operate more efficiently and experience fewer crises than those whose staff are unprepared. Thus, the purpose of this objective is to establish a responsive and effective staff development capacity in New Mexico.

At present, efforts to provide staff with needed training are not well coordinated. Generally, community service providers and institution officials are left to organize and provide staff training on their own. As a result, the system's overall capacity for assuring the competence of its direct care staff can be held in question. The issue is likely to grow more salient as plans to serve persons with severe disabilities in decentralized community settings are pursued.

Complicating matters is the absence of a large pool of qualified potential staff from which providers can fill direct care and management/program design positions. The university system in New Mexico generally does not offer students instruction in effective habilitative practices or contemporary service approaches. Additionally, owing in part to the relatively modest community system presently in place, few people in the state already have the needed skills.

One approach to this problem is to recruit qualified persons from other states. Other rural states, facing a similar dilemma, have taken this course with some success. This tactic, however, is not a long term solution. While helping to satisfy immediate needs, it does little to address the real problem. Ultimately, the Developmental Disabilities Bureau must be capable of staffing its system with qualified New Mexico residents.

Toward that end, the Institute recommends that a more centralized and systematic approach to staff development be undertaken. Specifically, the Developmental Disabilities Bureau is advised to set resources aside to sponsor a coordinated staff development program. Requests for Proposals regarding this program may be issued, but one option worth exploring is to develop a performance contract with a group of present service providers (e.g., through the existing provider organization).

The organization would be charged with:

- establishing a modest administrative structure for the program;
- hiring seven or eight "regional staff instructors" to develop a basic staff development curriculum, provide staff training throughout the state, and offer crisis assistance to providers (Numerous curricula and useful models for achieving this end already exist);
- establishing a central reference resource (i.e., materials library) for providers to draw on as needed;
- developing a directory of professional specialists (e.g., behavior, language instruction) for providers to draw on as needed; and
- assuring that the content of provided instruction is in line with the service philosophy and ploicy directions pursued by the Developmental Disabilities Bureau.

Developing a responsive staff development system such as the one posed above is crucial to the success of this residential plan. Providers asked to accommodate difficult to serve persons and burdened with unskilled staff will require equal access to well organized training activities that furnish state-of-the-art information and guidance. Moreover, given the presence of numerous persons with behavior problems, providers will need to be assured that knowledgeable persons will be available to difuse crises, develop specialized programs and help staff to implement such programs.

29. Establish a Crisis Management Capacity.

Crises are best dealt with through pevention. However, given the special needs of many persons with developmental disabilities, staff will occasionally be confronted with situations requiring the expertise of a specialist or some other supportive intervention. In anticipation of such events, the purpose of this objective is to design and implement an effective crisis management capacity.

The Developmental Disabilities Bureau should work with advocates, casemanagers and service providers to design a crisis management policy that encompasses at least these five components:

- Administrative structure and follow-up. Given the advent of some crisis, procedures must be developed whereby the response may be integrated into the client's overall treatment plan. Certainly, in the event of an emergency, staff must react as they see fit (e.g., call an ambulance). As the crisis unfolds, however, the casemanager must be informed and concerned parties (e.g., the client, parents, service providers) must be convened to promote a coordinated approach to the problem;

- Personnel/Specialists. In response to some crises, professionals with proper expertise must be consulted. The regional staff instructors and persons listed in the resource directory (See Objective 28) can play a useful role in this regard;

- Facilities/Equipment. In the event of a medical emergency, access to proper medical services must be assured. Given extreme maladaptive behavior, however, back-up systems within the service continuum must be in place. In anticipation of clients who simply "must be moved" due to their behavior, the Institute advises that one bed in each district, perhaps two beds in district 3, be left vacant (though reimbursed by the state). Clients having extreme and irreconcilable problems in one place may fill the vacant slot, provided staff at the new location are properly prepared. The vacated bed could then be used for any other client in crisis. Additionally, when not in use, vacant beds could be used to provide emergency respite care for persons living at home.

  The Institute recognizes the complexity of building an effective crisis management capacity. At first, few community providers may be willing to accommodate difficult to serve clients, let alone accept ones in crisis from other programs. Before settling on any single approach to the problem, solutions undertaken by other rural states (e.g., Nebraska, Montana) ought to be explored;

- Staff Support/Preparation. As noted in Objective 28, proper staff preparation is essential for preventing crises. Once in crisis, however, staff must be provided the technical support and guidance necessary to boost their confidence, provide them with needed specialized skills, and help them with implementing specially designed programs; and

- Standards/Guidelines. When responding to crisis situations, care must be taken to assure that the client's interests are protected and that overly restrictive approaches are not attempted. Thus, standards and guidelines for governing the entire crisis intervention process must be promulgated.

After designing needed policy, the Institute advises that it be implemented regionally and built into other relevant facets of the residential plan (e.g., casemanagement policy, staff development, quality assurance). Essentially, the design and implementation of a crisis management capacity is considered a key element of an expanded community services continuum.

30. Develop Services for Urgent Need Groups.

Given the nature of this residential plan, successful completion of this objective is tied explicitly to completion of numerous other objectives. In fact, activities directed at actually developing services for those in urgent need of services (See Objective 7) cannot be undertaken until several other activities are completed (e.g., implementation of case management policy, implementing a new Title XIX Waiver). Assuming that prerequisite activities are completed, efforts to establish needed services for this group can be initiated according to the parameters set by Objective 8 and the schedule outlined by Objective 5.

31. Develop Service Options for Ongoing Expressed Demand.

Once activities to accommodate the urgent need group are well under way, efforts to reform or expand services for others in the system may begin. Again, these activities will be tied to the status of other prerequisite activities, suggesting an essential need for systems level planners to oversee the entire process. For instance, if providers are having problems coping with crisis events, efforts to serve addtional persons with behavior problems should be delayed in favor of upgrading the system's crisis management capacity. In contrast, if staff development practices prove exemplary, planners may decide to accelerate the establishment of novel service approaches such as supported employment or supervised apartments.

Given that prerequisite objectives have been completed satisfactorily, the services planned for this group (See Objective 10) can be established. The process, however, must follow those incremental steps dictated by the overall residential services plan (See Objective 6).

32. Establish Services for Supporting Families.

The purpose of this objective is to implement a comprehensive family support program in New Mexico (See Objectives 9 and 11). Realistically, the Institute does not anticipate that the Developmental Disabilities Bureau will be capable of initiating a statewide program at first, given all the other system reforms that are planned and obvious resource constraints. Thus, the Bureau should pursue a long term strategy involving:

- the establishment of one to three pilot projects serving 20-30 families each at the start of this plan's second year. Such programs will provide all with needed experience that could be used to improve the service approach and spur statewide interest in supporting families;

- the cooperation of other state departments, universities and various private interests to extend the revenue base for sponsoring needed programs; and

- the coordination of Bureau staff and advocacy groups to assist with public education activities and other efforts aimed at promoting public interest in supporting families.

Moreover, the Developmental Disabilities Council can play a useful role in achieving this objective. Following the lead of numerous Councils in other states, the New Mexico Council could:

- sponsor limited family support initiatives to demonstrate their utility;

- sponsor certain aspects of programs funded primarily by the Developmental Disabilities Bureau (e.g., program evaluation);

- sponsor special research initiatives to explore novel approaches to supporting families (e.g., private sector involvement); and

- promote public education and interest in supporting families by lobbying legislators, sponsoring a modest statewide conference on the topic, and systematically releasing information to the media.

In most states, establishing a statewide family support program has proven a difficult task, requiring coordinated effort over several years. In this light, activities in New Mexico should be designed to establish small successful programs at first, building a sound basis for program expansion over the long term.

33. Establish Ongoing Training Program for Casemanagers.

In many respects the success of this plan is dependent on the competent performance of client casemanagers. These persons will be charged with administering client intake and exit policy, initiating and tracking client service plans, and assuring that clients receive the type and amount of services specified.

To assure that they are well prepared to undertake these and other essential tasks, the Institute recommends that the Developmental Disabilities Bureau establish an ongoing training program for casemanagers. The purpose of this program will be to provide instruction to:

- Orient new casemanagers to the role they will be expected to play as well as to inform all casemanagers of any changes to service related policy;
- Familiarize casemanagers with contemporary habilitative practice, and the nature of developmental disabilities and its effects on client functioning. Typically, casemanagers, holding degrees in social work or related fields, have limited experience with developmental disabilities and would profit from this type instruction;
- Introduce other topics deemed necessary for casemanagers to perform their work competently.

Additionally, training sessions could be used to identify problems with current policies and to explore various solutions.

VII FINANCE*

The strategic objectives for funding and managing the finances of New Mexico's system of services for persons with developmental disabilities are three:

(1) maximize the number of clients in programs that fit their supervision and service needs,

(2) minimize the cost of these services to the state, and

(3) minimize the risk of a loss of federal financing participation in New Mexico.

There are a number of funding options (outside of special education funds) that can support developmental disabilities services in New Mexico. These sources are:

- Title XIX (Medicaid)
- Supplemental Security Income (SSI)
- Social Security Disability Insurance (SSDI)
- Title IV - E
- Title IV - B
- Developmental Disabilities Grant
- Vocational Rehabilitation
- Social Services Block Grant (Title XX)
- Private Funds

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* This strategy, particularly those portions relating to the Title XIX waiver, are taken directly from the work of Robert Gettings, Director of the National Association of State Mental Retardation Program Directors, and Brian Burwell of SysteMetrics. The work of Mr. Gettings was supported in part by a subcontract with the Human Services Research Institute funded by the New Mexico Department of Human Services (HSD); the work of Mr. Burwell was likewise funded through a purchase order to SysteMetrics from HSD.

TITLE XIX (MEDICAID)

-- Source of Funds: Federal and State

-- Match Required: Federal 69.39%, State 30.61%; formula changes every two years, based on per capita income

-- Flow of Funds: HHS to HSD to providers (state must adopt standards of the Health Care Financing Administration)

-- Criteria for Use: Most policy decisions remain at the federal level and are controlled by state plan requirements. State has choice among optional programs and optional client groups.

Mandated Clients

- Recipients and deemed recipients of AFDC
- Recipients and deemed recipients of SSI
- Individuals in licensed foster care facilities
- Individuals under a subsidized adoption arrangements
- Recipients of mandatory state supplemental assistance
- Newborns born to eligible Title XIX mothers
- Former AFDC recipients who lose AFDC eligibility for certain reasons

Optional Clients

- Medical institution for one month and income of no more than three times SSI level (300% group)
- Medically needy
- Child medical assistance program (child. under 21)
- Non-mandatory state supplement
- Title XIX waiver (to provide home/community based services to persons who would be eligible for Title XIX if in an institutional setting
- Persons in mental health institutions, under 21 and over 65
- Persons in tuberculosis institutions, under 65.

Allowed Use of Funds: Services provided by the New Mexico Medicaid program include mandatory services which are required by federal regulations and optional sevices.

SUPPLEMENTAL SECURITY INCOME (SSI)

-- Source of Funds: Federal (Social Security Administration)

-- Match Required: No

-- Flow of Funds: Cash benefits to eligible persons
(Maximum monthly federal payment -- Disabled $336)

-- Criteria for use: There are four basic groups who qualify:

1. Adults over the age of 18 who are disabled

2. An adult who meets the definition of statutory blindness

3. A child (under the age of 18) who is disabled

4. A blind child who meets the definition of statutory blindness

-- Persons who live in public institutions generally are not elibigle for SSI except:

1. Persons in a facility with no more than 16 may be eligible

2. Persons in a facility primarily to attend approved education or vocational training provided in the institution may be eligible.

3. If Medicaid is paying more than half the cost of a person's care in a private or public health facility, the person may be eligible, but the SSI payment is limited.

4. Persons who are temporary residents of a public emergency shelter can receive SSI payments for up to 3 months during any 12-month period.

-- Allowed Use of Funds: A minimum income level for the aged, blind, or disabled based on financial need.

SOCIAL SECURITY DISABILITY INCOME (SSDI)

-- Source of Funds: Federal (Social Security Administration)

-- Match Required: No

-- Flow of Funds: Cash Benefits to eligible persons based on work history (Average monthly payment: Category 1, $325, Category 2, $175; Maximum monthly payment $950)

-- Criteria for Use: There are three basic categories of persons who qualify:

Category 1. Disabled workers under 65 years of age if the worker has been employed or self-employed long enough and recently enough under Social Security.

Category 2. A person continuously disabled since childhood (before age 22) if a parent is covered under Social Security.

Category 3. A disabled widow or widower aged 50-60 if the deceased spouse was covered under Social Security.

-- Allowed Use of Funds: Cash benefits to disabled workers (and their dependents) who have contibuted to the Social Security Trust Fund through the FICA tax on earnings (i.e., have an "earned right" to benefits).

-- Most developmentally disabled dependents of SSDI workers are eligible for SSI as well as SSDI upon reaching age 18.

TITLE IV-E

-- Source of Funds: Federal matching funds for states

-- Required Match: State/30.61; Federal/69.39% (based on eligible clients)

-- Flow of Funds: Federal reimbursement to state for maintenance payments for eligible clients in foster care and adoption subsidy.

-- Criteria for Use:

-- Must have a federally approved state plan that includes:

1. Reasonable effort requirement -- a range of services must be offered and provided in an attempt to prevent removal of the child from the home, and to reunify the family.

2. A case review system.

3. Case plan requirements - the case plan for each child must:

- be a written document, which is a discrete part of the case record, in a format determined by the state, which is available to the parent(s) or guardian of the foster child.

- be developed within a reasonable period, to be established by the state, but in no event later than 60 days starting at the time the state agency assumed responsibility for providing services including placing the child.

- include a discussion of how the plan is designed to achieve a placement in the least restrictive (most family-like) setting available and in close proximity to the home of the parent(s), consistent with the best interests of the child.

- include a description of the services offered and the services provided to prevent removal of the child from the home and to reunify the family.

-- Eligible clients are those who were eligible for or receiving AFDC at the time of entering foster (adoption subsidy for clients eligible for AFDC or SSI at time of termination of parental rights).

-- Allowed Uses of Funds:

1. For foster care maintenance and adoption assistance for eligible children -- reimbursement.

2. For state and local training for foster care and adoption assistance (federal participation is 75% for training)

3. For other state and local administrative expenditures for foster care and adoption assistance (federal participation at 50%), including determination and redetermination of eligibility, fair hearings and appeals, rate setting and other costs directly related to the administration of the foster care program; other examples include

- referral to services
- preparation for and participation in judicial determinations
- placement of the child
- development of the case plan
- case reviews
- case management and supervision
- recruitment and licensing of foster homes and institutions
- rate setting
- a proportionate share of related agency overhead.

TITLE IV-B (CHILD WELFARE)

-- Source of Funds: Federal matching funds for states

-- Match Required: Yes - 25% state, 75% federal

-- Flow of Funds: Grant-in-aid from federal to state for child welfare services

-- Criteria for Use:

-- Must have a federally approved child welfare services state plan that must include:

1. A description of child welfare services provided to children and their families, and specify the geographic areas where services will be available.

2. Which preplacement preventive and reunification services are available to children and families in need.

-- Must meet case plan requirements listed for Title IV-E

-- Must have HSD approval in terms of case planning

-- Eligibilty is based on need for the service

-- Allowed Uses of Funds:

- 24-hour emergency caretaker services
- homemaker services
- day care
- crisis counseling
- individual and family counseling
- emergency shelters
- procedures and arrangements for access to available emergency financial assistance
- arrangements for the provision of temporary child care to provide respite to the family for a brief period, as part of a plan for preventing children's removal from home
- self-help groups
- services to unmarried parents
- provision of, or arrangements for, mental health, drug and alcohol abuse, and vocational counseling, or rehabilitation

DEVELOPMENTAL DISABILITIES GRANT

-- Source of Funds: 100% federal

-- Match Required: No

-- Flow of Funds: State Developmental Disabilities Council distributes funds through contracts.

-- Criteria for Use: Activities must accomplish goals and objective of the Developmental Disabilities Council Plan and must be approved by the Developmental Disabilities Council.

-- Allowed Uses of Funds:

-- Grants to agencies for activities that assist state n completing goals and objectives in the Council plan

VOCATIONAL REHABILITATION

-- Source of Funds: Federal and State (U.S. Department of Education

-- Match Requirement: Yes -- 80% federal, 20% state; In the case of individuals on SSI, the amount is 100% federal.

-- Flow of Funds: Grant from federal level to state vocational rehabilitation agency to provide or purchase services, amount determined by per capita income and population.

-- Criteria for Use: Clients must have a handicapping condition as identified by a medical professional. The condition must result in substantial vocational limitation. It also must be expected that after services are provided the person will be able to be employed.

-- Allowed Use of Funds: Funds may be used to provide whatever services are needed to determine the client's eligibility for service or are needed to enable the person to enter employment.

SOCIAL SERVICES BLOCK GRANT (TITLE XX)

--Source of Funds Federal and State

-- Flow of Funds: Dollars appropriated by Congress then further appropriated by state legislature and a pre-expenditure report is filed. Client eligibility is determined and services are provided by staff directly or purchased through a contractual arrangement with an agency for the client.

-- Criteria for Use: Federal government requires that services must meet one of the follwoing goals:

1. Achieving or maintaining economic self-support or prevent, reduce, or eliminate dependency

2. Achieving or maintaining self-sufficiency, including reduction or prevention of dependency

3. Preventing or remedying neglect, abuse, or exploitation of children and adults unable to protect their own interests, or preserving, rehabilitating or reuniting families.

4. Preventing or reducing inappropriate institutional care by providing for communiyt-based care, home-based care, or other forms of less intensive care

5. Securing refferral or admission for institutional care when other forms of care are not appropriate, or providing services to individuals in institutions

Recipients of AFDC, SSI and SSDI are categorically eligible. Otherwise, eligibility factors include:

- need for service: (applies to all)
- income eligible (applies to some)
- resident of area where service is provided (applies to some)

Pursuant to the finance objectives, the most important funding streams are the entitlement programs in which the federal share is high or even 100% and the potential dollar amount is unlimited. The Medicaid program, particularly the Title XIX Waiver program, in which New Mexico is allowed to provide less costly and more appropriate plans of service to current or prospective ICF-MR residents has the most potential of any of the funding streams. However, given the federal drive to contain Medicaid costs, the state must contend with increasingly stringent eligibility and coverage restrictions and federal oversight, and must face the likelihood that these funds will be capped some time in the future.

34. Prepare New Medicaid Waiver Application and Strengthen the Management of the Waiver Program

34.1 Background

At present New Mexico is not prepared to meet the conditions of the original Waiver submitted three years ago. Several developments have significantly reduced projected savings under the Waiver, mainly:

- the Legislature's decision to maintain the current capacity of Fort Stanton rather than reducing it by a total of 80 beds during years II and III of the Waiver program;
- the decision to submit a second developmental disabilities Waiver request covering non-institutionalized, medically fragile children, thus, offsetting, to a significant degree, the favorable cost comparison contained in the state's original Waiver request; and
- the certification of 22 additional community ICF-MR beds (10 at New Horizons and 12 at El Mirador) not included in the projected years II and III institutional bed count in the state's original Waiver request.

These events have led HED to limit enrollment in the Waiver in order to keep within its overall ceilings for total long term care costs (Waiver costs plus ICF-MR costs) as originally projected, and thus only 15% of the projected FFP has been generated (Burwell, 1985). The Waiver must be renewed by June 30, 1986 or New Mexico will have to cover the loss of approximately $600,000 in FFP. Fortunately, legislation now before Congress would require the Health Care Financing Administration (HCFA) to approve any renewal request at least for a year. This will give New Mexico time to submit a new Waiver request.

34.2 Waiver Provisions

HSRI recommends that New Mexico submit a new waiver application that provides for the phase down of Fort Stanton and Los Lunas Hospital and Training Schools. The major reasons for this recommendation are four.

- By our projections, though admittedly not as refined as we would have liked, New Mexico does not require additional ICF-MR beds overall. As explained in previous sections, though some communities do need additional small ICF/MR facililities, these can be offset by reducing the census at Fort Stanton and Los Lunas by transfering those clients not requiring high supervision, medically-oriented care to the community.

- An alternative waiver application that proposes to delimit ICF-MR bed development without reducing the population at Fort Stanton and Los Lunas would effectively limit the development of needed ICF-MR facilities in the communities.

- The likelihood of HCFA approval of an alternative waiver that proposes to deflect institutional placements is significantly less than the likelihood of the approval of a Waiver targeted on deinstitutionalization of individuals at Fort Stanton and Los Lunas. Quotes from Gettings and Burwell support this assertion:

First and foremost, with each passing month HCFA officials appear to be requiring more and more rigorous documentation of a state's assumptions about the future growth in institutional LTC capacity. Consequently, it is becoming increasingly difficult to cover non-institutionalized "at-risk" populations under a Section 2176 waiver program. Generally, a state must be able to present hard evidence that the number of beds needed to accommodate the "at risk" population are already accounted for "in the pipeline" (e.g., certificates of need have been approved or capital dollars appropriated) and, therefore, are certain to be added to the state's existing SNF, ICF or ICF-MR capacity in the absence of the requested waiver program. Assertions regarding the likely growth in demand for nursing home/institutional beds, based on either trend data or surveys of actual unmet needs, that are not supported by evidence or an impending increase in institutional bed capacity sufficient to meet such needs are now scrutinized very closely by HCFA officials. Because HCFA has no measurable criteria for determining the level of documentation required, it is not possible to say with absolute certainty the number of "at-risk" clients a state will be allowed to cover; furthermore, the applicable circumstances differ from state to state and, as a result, a particular state may be in more or less advantageous position to make a case for growth in institutional bed capacity should its proposed waiver program be disapproved. However, in tracking DD-related waiver requests over the past six months, I can certainly report that HCFA generally has been permitting states to include fewer and fewer non-institutionalized recipients under their waiver programs, as compared to a year or more ago. (Gettings, 1984)

The chance of securing HCFA's approval for a new waiver program would undoubtedly be strengthened if it is tied to a long-range plan for the closure of Fort Stanton. Total FY 74 expenditures for Fort Stanton under Medicaid will amount to about $4.5 million. If these Medicaid expenditures were redirected into the community under the Medicaid waiver, reductions in Medicaid revenues at Fort Stanton could be used to finance needed community services at the same level of Federal participation (69.7%). (Burwell, 1985)

- Finally, HCFA may soon move to limit the amount of federal financing participation (FFP) that a state could claim for any particular level of long term care (SNF, ICF and ICF-MR). A ceiling would be established, probably based on the average statewide cost of care for similar recipients. Depending on how such a rule was administered, it could have a negative fiscal impact in New Mexico where state-operated ICF-MR facilities have higher reimbursement rates than the privately operated facilities (Gettings, 1984). In other words by continuing to maintain the current census levels at Los Lunas and Fort Stanton, New Mexico is opening itself to some future loss in federal financing participation.

34.3 Waiver Management

HSRI endorses the recommendations of Gettings and Burwell that:

- HED should carry prime responsibility for administering the waiver, with HSD maintaining that oversight necessary to assure compliance with HCFA rules and regulations and with the provision of the waiver agreement;
- HED should have a full time manager to direct all Waiver activities in New Mexico. This manager should have staff resources necessary to fulfill New Mexico's obligations under the waiver program;
- an adequate number of case managers must be employed;
- the eligibility determination process must be strengthened and streamlined;

35.0 Take Full Advantage of Other Funding Options

Despite New Mexico's best efforts, there is no assurance that HCFA will approve the Waiver Application. Therefore, the prudent course of action is to explore other sources of funding while New Mexico's renewal request is being prepared and processed. These alternatives are far less desirable than the Medicaid Waiver both from a programmatic and fiscal viewpoint.

Programmatically, New Mexico may have little choice but to develop additional IFC-MR beds thereby providing higher levels of supervision and support than needed for many clients. The use of

ICF-MR facilities for clients requiring less than "round-the-clock" medically-oriented care will violate the programmatic principles of least restrictiveness and normalization. Moreover, though New Mexico's absolute expenditure per client for ICF-MR's may be less than it would for non-Title XIX residential alternatives, the total amount is greater. Thus depending on the extent to which federal financing participation under Title XIX is limited in the future, the current financial of ICF-MR's advantage to New Mexico could evaporate.

New Mexico will also have to take greater advantage of non-Title XIX funding streams (e.g., Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Titles IV-B, and IV-E, and private capital). However fuller use of these options will not fully cover the losses associated with the loss of the Title XIX Waiver Program.

35.1 Explore Other Title XIX Medicaid Objectives

Mr. Getting's report entitled "Potential Uses of Medicaid Funding in New Mexico's Community MR/DD Program" (April, 1986) describes other Medicaid funding alternatives at length. Accordingly, we have included only a general review of these options. HSRI recommends that HSD consult Mr. Getting's report (prepared for the Bureau of Developmental Disabilities, Health and Environment Department) for guidance in this area.

35.1.1 Assess the Development of Community-Based ICF-MR Facilities

This option demands a significant commitment of staff time and resources to mount a successful statewide community ICF/MR development program for converting existing state-supported group residences to ICF/MR certified status (as has occurred in some other states). However, the potential number that could be converted is limited and new state funds would have to be obtained to meet the non-federal share of the cost of operating such newly certified ICF/MR facilities. Finally, the ICF/MR approach generally involves much greater costs because: a) it ties eligibility to need for 24-hour care, thus acting as an inducement to out-of-home placement and the provision of a complete "package" of services; and (b) services must be provided in accordance with a detailed set of federal standards that allow states and vendor agencies less flexibility to control the cost and appropriateness of services.

These drawbacks notwithstanding, this approach to financing services appears less susceptible to the vagaries of current federal policies than do other possible approaches.

35.1.2 Explore Fuller Use of Optional Medicaid Reimbursable Services

The second approach that might be explored is to cover certain selected community day programs for the developmentally disabled as optional Medicaid reimbursable services. States that have elected this approach have generally used either the clinic (42 CFR 440.90), rehabilitation (42 CFR 440.130(d), or personal services (42CFR 440.170(f)) options under existing federal regulations as the basis for claiming such reimbursement. Although relatively few states have elected to pursue such options (primarily due to the lack of clear-cut federal policies in this area and concerns about the cost implications of making such services available), such optional coverages would allow New

Mexico a means to tailor day services to the particular needs of severely disabled adults, without tying eligibility to the setting in which the recipient lives (as in the case of ICF/MRs). One major drawback of this approach is that the cost of congregate care - usually the most expensive element of a the service plan - would not be Medicaid reimbursable.

Another drawback is that HCFA has always discouraged states from using such optional service lines of the Medicaid regulations to finance long term care services and, since the advent of the Section 2176 waiver program, has generally refused to approve state plan amendments that contemplate such action. (Gettings, 1984)

35.2 Supplemental Security Income/Social Security Disability Insurance

HSRI could obtain no reliable figures from other states by which to gauge whether New Mexico is taking full advantage of the SSI and SSDI programs. HSRI expects to have these figures within the next few months and to provide them to officials in New Mexico as part of the Developmental Disabilities Strategic Planning Model (discussed elsewhere).

If these interstate comparisons indicate that New Mexico does not appear to have all qualified persons eligible, then HSRI recommends that the Developmental Disabilities Bureau mount an aggressive program to do so. The addition of persons in state-funded programs to the SSI/SSDI rolls would reduce the demand on state funds.

Two categories of individuals that state agencies tend to neglect are:

- those individuals on SSI who upon turning 18 become eligible for SSDI as well by virtue of their having been disabled since childhood and being dependents of SSDI workers. Obtaining SSDI benefits for SSI/Medicaid eligible persons would carry the added benefit of rendering them eligible for Medicare PART A (Hospital) coverage thus reducing the demand on Medicaid.
- those children in foster care under Title IV-E who are disabled and thus potentially eligible for SSI when they turn 18 and lose their Title IV-E eligibility. The state should identify these children as soon as possible in an attempt to get them on the SSI rolls and off the Title IV-E rolls before they turn 18.

35.3 Titles IV-B* and IV-E

There are a number of recommendations in this area which may be worth pursuing in New Mexico.

35.3.1 Explore the Use of Title IV-B Funds Not Only for Foster Care, but for In-Home Family "Support" Services as Well

Federal provisions are relatively loose in terms of the types of child welfare services for which Title IV-B funds may be used.

35.3.2 Identify More Foster Care Cases as IV-E Eligible

In response to this recommendation. Printouts could be sent ot the field to review cases that potentially could be IV-E.

35.3.3 Identify More Foster Care Cases as SSI Eligible

For the identification of more SSI eligibles, a printout could be sent to the field listing non-SSI children in voluntary placements over six months or with excessive medical costs. Field workers could review each case to assure that all of the possible SSI eligibles are identified.

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* These recommendations are taken from recommendations prepared by William Copeland, Copeland and Associates, for the Iowa Developmental Disabilities Council (1985).

35.3.4 Claim Retroactive Payments Back for Two Years on Newly Identified IV-E and SSI Eligibles

Clearly the ability to claim retroactivate payments increases the potential payoff from an agressive eligibility program.

35.3.5 Charge More Expenses in Foster Care to "Maintenance" Rather Than Service Costs, so that a Larger Percentage of Foster Care Expenditures Could be Charged to IV-E

For example, to the extent that at the present time the cost of daily supervision provided by child care staff is billed as a service cost and, therefore, paid with Social Service Block Grant (SSBG), Title IV-B of state dollars, it could be instead be billed as maintenance and, therefore, for IV-E eligibles, 69.39% of the cost would be paid with IV-E dollars.

35.3.6 Change the Definitions of Service and Administration in Various Areas of Foster Care to Increase the Size of IV-E Claims

This will correspondingly reduce the amounts required from SSBG, Title IV-B or state funds. For example, costs for case planning, review and management, and recruitment and licensing may be currently being billed as service. Redefining such costs as administrative would allow them to be billed to IV-E, which would allow federal financial participation (FFP) at the rate of fifty percent.

35.4 Private Capital

New Mexico is fortunate to have a number of entrepreneurs in the field who have been able to successfully attract private capital - their interest owing in some part to the tax advantages associated with real estate investment. So long as these developments are consistent with New Mexico's residential plan, HSRI recommends that the state do everything possible to encourage private initiatives.

Similar efforts have been initiated in other states that New Mexico may wish to consider, such as:

- the setting up of trusts or family non-profit organizations to purchase residences for developmentally disabled family members,
- the development of cooperative housing arrangements for persons with developmental disabilities,

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- the use of limited partnerships and syndications to marshall private capital for the purpose of constructing needed facilities

  Martin Legault, Executive Director
  Corporation for Independent Living
  Hartford, CT
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Other sources of private funds for the operation of services for persons with developmental disabilities that New Mexico may wish to take greater advantage of are:

- charging for services on a sliding scale according to parental income (both institutional and community services),
- encouraging advocacy groups and others to set up non-profit (501)(c)(3) shells for the purpose of accepting tax deductible contributions from concerned individuals and corporations.

36.0 Strengthen and Streamline Financial Management Procedures

36.1 Assess Current Rates

HSRI strongly recommends that the Developmental Disabilties Planning Council undertake an independent assessment of the rates now afforded providers of service to persons with developmental disabilities in New Mexico. The assessment should cover both current services and those new services recommended in this plan. The Council should use the results of this assessment to advocate for rates sufficient to support adequate levels of service in the community. In the interim, the Council can make use of the service cost standards provided with the Developmental Disabilities Strategic Planning Model as a basis for assessing the adequacy of community service rates.

As in most states, amounts allocated to providers of service in New Mexico are limited by the amount of state funds appropriated each year. Over the years, limited appropriations have contributed to the steady erosion of rates relative to the costs of the resources required to provide the services. At the provider level, this has forced the payment of lower wages and fringe benefits, the toleration of staff turnover and staff vacancy rates, and so forth. Likewise, funding for staff training, specialized consultation and technical assistance, emergency services, and other support services essential for a healthy system have suffered and in many areas have never been forthcoming. Consequently, providers are forced into custodial modes of service in much the same insidious way as institutions have been in years past.

37. Establish a Statewide Budget Process That Provides for the Preparation and Approval of Regional Plans and Budget Requests Consistent with Explicit Statewide and Regional Priorities

Historically, legislative funding of service providers in New Mexico reportedly can be correlated with the aggressiveness of particular advocacy groups and providers. Such advocacy has been enormously important in establishing services in the community, although at this stage in the development of the service system, the legislature should be presented with funding requests keyed to regional and statewide plans for system expansion and modification. These plans should target those services and those clients most in need and should provide for the system supports (infrastructure) essential to the provision of effective and appropriate plans of services for clients.

HSRI also suggests that in order to free service agency administrators and state staff time for planning, the annual Request for Proposal submission and review process be extended from one to two years. As it is now, a disproportionate amount of executive time must be spent submitting, resubmitting, reviewing, and rereviewing grant requests - time that could far better be spent in coordinated, regional level and state level planning.

VIII. INTERAGENCY COOPERATION

Services made available through the Developmental Disabilities Bureau do not exist in isolation. Other components of the human services and educational systems have responsibility for delivering certain needed services to Bureau clients. Moreover, these complementing responsibilities do not stay constant, but evolve as client needs change or as divisions of labor within government systems are altered. As a result, to establish a coherent service approach that makes efficient use of available resources, the Developmental Disabilities Bureau must establish means for promoting ongoing cooperation between various relevant government agencies.

38. Revise Interagency Arrangements Regarding HED and HSD.

As noted elsewhere in this plan (See Objective 21), the present organizational structure governing services to persons with developmental disabilities lacks coordination and focus. Key to correcting this problem is a revision of interagency arrangements regarding HED and HSD, especially with regard to the administration of the Title XIX Community-based Waiver.

As recommended by Objective 34, a crucial component of this plan is the implementation of a new Waiver agreement with the Health Care Finance Administration (HCFA). Waiver dollars would make it possible to develop community programs for persons presently at Fort Stanton and others with severe handicaps. New Mexico's administration of its current waiver program, however, is plagued by numerous problems. In his report to HSD regarding the waiver's implementation (Systemetrics, 1985), Brian Burwell notes that:

> Most of the problems associated with the existing waiver for the developmentally disabled can be attributed to the administrative division of its operation across HED and HSD. This division leads to diffused accountability, communication problems, and administrative inefficiencies (p.10).

Additionally, Burwell notes that these and other related problems will likely continue until responsibility for the waiver is vested under one agency.

The Institute understands the importance of securing a Title XIX waiver and implementing it with great efficiency. Toward that end, the Institute strongly recommends that officials at HED and HSD begin discussions aimed at revising their current cooperative agreement for joint administration of the waiver program. Ideally, this new relationship would place full responsibility for the waiver within HED. HED already is already charged with developing a community based system for persons with developmental disabilities and has the most to gain from the successful implementation of the waiver. However, in acquiring full responsibility for the waiver, sufficient resources must be allocated to HED to acquire personnel with sufficient expertise and to undertake needed administrative functions.

39. Establish Means for Easing the Transition of Clients Through Normal Life Stages.

In establishing comprehensive systems that respond to a wide range of needs over the lifetime of individuals, divisions of responsibility are common. Public schools provide educational opportunities to persons in their early developmental stages.

The Department of Vocational Rehabilitation focuses on providing job related instruction and opportunity to adults. A separate government agency administers programs for senior citizens, while another specializes in directing federal programs such as Medicare or Medicaid. Regarding persons with developmental disabilities, the Developmental Disabilities Bureau is charged with providing a range of residential, vocational and support services to those seeking services. As clients age or as their needs change, however, they may require services made available through some other government agency.

In many states, coordination between various government agencies is unsatisfactory. For instance, in some states little is done to match the vocational instruction provided adolescents with disabilities in public schools with the type of work they will be asked to perform once they graduate and enter the adult services system. Likewise, as persons with disabilities reach retirement age, the adult service system provides few, if any, senior citizen day programs, while government agencies charged with accommodating the elderly do little to help. Obviously, such conditions do not benefit clients, undermining their habilitative progress by limiting the system's capacity for matching services with client needs. Further, individual agencies are prompted to provide all those services that are needed, wasting resources and compromising efforts to integrate clients into the overall community services network. As a result, as community-based systems evolve, numerous analysts have urged that cooperative agreements be struck between various government agencies to ease the transition of clients across

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persons with developmental disabilities into the community, however, will eventually require the cooperation of the entire human services network.

40. Evaluate Procedures for Coordinating with Native American Communities.

Numerous persons with developmental disabilities reside on Native American lands. Traditionally, services for these persons have been unsatisfactory as various factors have conspired to undermine efforts to establish needed programs, forcing many to leave their communities to obtain needed services. For instance, given that certain Indian lands cross state boundaries (e.g., the Navajo reservation), the states involved have not developed a coordinated policy for prompting development of needed programs. Further, there is a longstanding disagreement regarding the state's overall responsibility for funding programs. The states argue that the Tribal Councils are responsible for securing needed funds through the Bureau of Indian Affairs and other relevant sources. In contrast, facing chronic funding shortages, the tribes maintain that state funds (and their complementing federal dollars) should flow more freely across reservation boundaries. Complicating matters for the tribes is the pressing need to focus on solving ongoing economic problems that contribute to high unemployment and other social ills.

As New Mexico moves to reform its residential services system, it should seize the opportunity for evaluating its relationship with Native American communities. A desired goal of successful community integration is to provide needed services within the individual's home community. Toward that end, the Developmental Disabilities Bureau should initiate discussion with Tribal Councils in New Mexico:

- To identify practices that undermine efforts to establish programs on Indian lands;
- To explore means for allowing Native Americans who presently receive residential services off the reservation to return to their home communities;
- To explore means for securing the funds, perhaps through cooperative arrangements, for establishing needed services on Indian lands.

Eventually, such discussion must involve state officials from Utah and Arizona, including representatives of each state's Developmental Disabilities Council.

In reforming the state's approach to delivering residential services, the needs of Native Americans with developmental disabilities cannot be overlooked. Traditional responses to their needs have been unsatisfactory. However, with discussion and compromise, a comprehensive community based service system can be established on Indian lands as well. Already, toward that end the Navajo Tribal Council, in cooperation with Save the Children Federation, is preparing a needs assessment and plan directed at improving the Tribe's response to disability. The Institute encourages the Developmental Disabilities Bureau to participate in that planning process and to promote similar efforts on other reservations.

33. Establish Ongoing Training Program for Casemanagers.

In many respects the success of this plan is dependent on the competent performance of client casemanagers. These persons will be charged with administering client intake and exit policy, initiating and tracking client service plans, and assuring that clients receive the type and amount of services specified.

To assure that they are well prepared to undertake these and other essential tasks, the Institute recommends that the Developmental Disabilities Bureau establish an ongoing training program for casemanagers. The purpose of this program will be to provide instruction pertaining to:

- Orientate new casemanagers to the role they will be expected to play as well as to inform all casemanagers of any changes to service related policy;
- Contemporary habilitative practice, and the nature of developmental disabilities and its effects on client functioning. Typically, casemanagers, holding degrees in social work or related fields, have limited experience with developmental disabilities and would profit from this type instruction;
- Other topics deemed necessary for casemanagers to perform their work competently.

Additionally, training sessions could be used to identify problems with current policies and to explore various solutions.

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APPENDIX A

PROVIDER SURVEY FORMS

AGENCY SURVEY FORM

Please fill-in blank spaces and correct any incorrect information provided

____
Name of Agency

1. Number of Clients Served (Unduplicated Count)

a. _______________. Total number of active clients as of March 31, 1985.

b. _______________ Number reported under the Client Oriented Option Profile (COOP) system as of March 31, 1985.

c. _______________ Number not reported under COOP (if any)

d. Please describe the ways in which those persons not reported under COOP differ from those reported (e.g., not HED-funded, time lag, ...)

2. SSI/SSDI Participation

a. _______________ Number of clients receiving Supplemental Security Income (SSI) payments as of March 31, 1985

b. _______________ Number of clients receiving Social Security Disability Insurance (SSDI) benefits as of March 31, 1985

3. _______________ Number of families having sought or received services from your agency and known to have since had to relocate or make arrangements to receive needed MR/DD services in other states over the last three years

SURVEY OF AGENCIES PROVIDING SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES IN THE STATE OF NEW MEXICO

____
Agency Name

____________________________, ________________, and
Name Title

____ of person
phone Number

primarily responsible for completing this survey.

Programs Provided by Agency:

Please Check:		Year Agency First Began Providing Program
	HABILITATIVE	
	CHILDREN/ADOLESCENT PROGRAMS	
________	Pre-School	____________
________	Special Education	____________
________	Day Program	____________
	ADULT DEVELOPMENTAL PROGRAMS	
________	General Activities	____________
________	Daily Living Training	____________
________	Pre-Vocational	____________
________	Work Activity*	____________
________	Sheltered Workshop*	____________
________	Mobile Work Force Teams or Work Stations in Industry*	____________
________	Job Placement/Follow up*	____________
________	Post-Vocational*	____________
	RESIDENTIAL	
________	Skilled Nursing/Extended Care*	____________
________	Intermediate Care Facilitie -- MR/DD*	____________
________	Residential - High Supervision*	____________
________	Residential - Moderate Supervision*	____________
________	Residential Minimum Supervision*	____________

For each program checked above, please complete one program survey form.

Return this cover sheet, the agency survey form and all program survey forms to Human Services Research Institute, 120 Milk Street, Eighth Floor, Boston, MA 02109.

A postage-paid envelope is enclosed.

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* See definitions. Definitions included for program categories other than those used in the COOP reports.

PROGRAM SURVEY FORM

________________________ Name of program

1. Number of Clients Served

a. ____________ Total number of active clients as of March 31, 1985.

b. ____________ Number reported under the Client Oriented Option Profile (COOP) system as of March 31, 1985.

c. ____________ Number not reported under COOP (if any)

d. Please describe the ways in which those persons not reported under COOP differ from those reported (e.g., not HED-funded, time lag, ...) (please use back of page)

e. ____________ Total number of clients the program was capable of serving as of March 31, 1985

2. Client Levels of Functioning (See Instructions)

a. ____________ Estimated number of active clients with severe medical/physical problems

b. ____________ Estimated number of active clients with moderate medical/physical problems

c. ____________ Estimated number of active clients with endangering behavior problems

d. ____________ Estimated number of active clients with disruptive behavior problems

e. ____________ Estimated number of active clients with minimum adaptive skills

f. ____________ Estimated number of active clients with moderate adaptive skills

g. ____________ Estimated number of active clients with high adaptive skills

3. Client Movement

a. ____________ Number of individuals applying for program or who would have participated in program had space been available in 1984

b. ____________ Number of persons that applied in 1984 but whom you could not accept for service. Please outline chief reasons why in order of importance (e.g., behavior problems, medical problems, need for special physical assistance, limited capacity, lack of funding) (please use back of page)

4. Clients Wait Listed (please count all persons awaiting service whether or not they are on a formal waiting list)

a. ____________ Total number of individuals on waiting list (If the waiting list is shared with other agencies, name these agencies: ________________________)

b. Urgency

____________ Number of wait-listed individuals whose circumstances pose an immediate underlying threat to the health or the safety of the individual or others., e.g.: no place to live, an abusive situation, . . .

____________ Number of wait-listed individuals whose current circumstances are not adequate, e.g. inadequate food, shelter, clothing, care and treatment, right to privacy, dignity, respect.

____________ Number of wait-listed individuals whose current circumstances are not appropriate e.g., supportive family situation but not able to meet individuals habilitative training needs

____________ Number of wait-listed individuals whose current circumstances are not the least restrictive feasible alternative, e.g., living in a situation not age appropriate, (i.e., with parents), or a physically handicapped person living in a home not fully accessible

____________ Number of wait-listed individuals for whom alternative circumstances are desired or necessary for any other reason.

c. ____________ Longest period of time (months/years) an individual has been on the current waiting list.

d. ____________ Average period of time a person must stay on the current waiting list.

5. Staffing

a. ____________ Number of full time equivalent (FTE) staff

b. ____________ Number of FTE staff whose primary responsibility and largest amount of time is spent working face-to-face with clients

c. ____________ Number of additional staff if any required to adequately supervise/manage clients now in the program

6. Cost/Funding

a ____________ Total Cost Fiscal Year 1983-1984
b. ____________ % State General Funds
c. ____________ % Other State Funds (not including Medicaid
d. ____________ %Medicaid/Supplemental Security Income (SSI)
e. ____________ %Other Federal Funds (not including Medicaid or SSI)
f. ____________ %Private (1st or 3rd Party)
____________100%

Please fill-in blank spaces and correct any incorrect information provided

APPENDIX B

GUIDE FOR INTERVIEWING KEY ACTORS AROUND NEW MEXICO

KEY INFORMANT INTERVIEW QUESTIONS

RESIDENTIAL PLANNING FOR THE DEVELOPMENTALLY DISABLED

1. How are you involved, i.e. what is your role, in residential services for the developmentally disabled in New Mexico.?

2. What governs your involvement, e.g. governing bodies, regulations, etc.?

3. With what other agencies, boards, groups, or other entities must you work closely in order to fulfill your role with respect to residential services?

4. Do you work with a specific definition of the developmentally disabled or with the handicapped?

5. What do think are the strengths of the residential services for the developmentally disabled in New Mexico?

6. What are the unmet needs of the developmentally disabled in New Mexico?

7. What are the barriers to meeting those needs?

8. What alternatives can you suggest to overcoming those barriers?

9. What is the role of state government in meeting the residential needs of the developmentally disabled? What is the role of the family and others?

10. Do you have any plans to try any of the alternatives proposed above for meeting the needs of the dd population? If so, what and how?

11. What has been tried successfully and/or unsuccessfully in the past to improve the residential service needs of the dd population?

12. What information needs, resources, or other needs have inhibited you from achieving your goals for residential services?

13. How would you summarize the situation today or the key issues in residential services?

14. Want do you want or expect to get from this residential services plan for New Mexico? Who else do you suggest we contact for important information?

Questions for agencies involved in providing direct services:

1. What services does your agency provide to clients receiving residential services from the state of New Mexico?

2. Does your agency have a plan for services; standards, regulations, and/or program guidelines?

3. Is service quality monitered? How?

4. What is the amount of expenditures for services mentioned above at the present time and in the past two years?

5. Is the population benefitting from these services also served and counted by another provider? Who?

6. Does state or federal legislation which has recently been enacted seem to be affecting your operations?

APPENDIX C

DESCRIPTION OF SEVEN LEVELS OF FUNCTIONING CATEGORIES

Seven level-of-functioning groups are defined below. In deciding in what group clients best fit, consider each group from one -- seven, in that order. In those cases when a client could conceivably fit into two or more groups, s/he should be shown in the lowest-numbered group (i.e., lowest functioning group).

The medical disability category (1) includes those persons whose medical problems are severe enough to demand continued attention from medically trained personnel. The physical disability category (2) includes those persons whose physical impairments demand personal care services above and beyond that required for persons with developmental disabilities but without such physical limitations. The behaviorally-related categories 3) and 4) include those persons whose behavioral problems are severe enough to require supervision, controlled environments and behavior management measures that are above and beyond those required for persons with developmental disabilities but without these behavioral problems. Persons assigned to one of the habilitative categories (5 - 7) have no overriding medical, physical or behavioral problems that demand an extra level of care and that hold their adaptive skills below what they otherwise might be.

1. Persons with Chronic and Serious Medical Problems

   o have serious and chronic medical conditions requiring continual medical attention

   o taking medications that must be administered by medically trained persons and where monitoring is required to monitor side effects and to assure proper administration (e.g., having diabetes and requiring frequent insulin injections);

- bedridden 24 hours a day (nonambulatory)
- incontinent (no level of bowel or bladder control)
- life threatening condition that requires 24 hour monitoring and rapid access to medical care
- life support equipment required
- uncontrolled seizure activity
- alcohol or drug addiction

2. Persons with Severe and Chronic Physical Impairments

Persons able to perform few or no self-care activities and few or no other activities of daily living unaided due primarily to serious and chronic physical impairments

- severe auditory, visual, or cognitive impairment does not interact or relate to environment
- does not feed self
- must be dressed/undressed completely
- does not tend to own personal hygiene
- needs help using prosthetics or similar devices
- needs special help getting around
- history of seizures requiring continual monitoring

3. Persons with Endangering Behavior Problems

- exhibit behaviors dangerous to themselves (e.g., head banging, pica, copography and self biting) or to others (e.g., physical attacks, forceable sexual advances);
- exhibit behaviors destructive to property (e.g., arson);
- regularly refuse staff requests or are nonattentive to their surroundings in situations where their well being or that of others is seriously jeopoardized (e.g., runs, away, runs in front of cars, . . .).

4. Persons with Disruptive Behavior Problems

- exhibit endangering and destructive behaviors infrequently and with ample warning so that they can be managed without constant monitoring in a controlled environment;

- exhibit less serious behavior problems such as disrupting others activities. and minor damage to property:
- ignore staff requests of minor consequence in terms of client well-being (e.g., use profane or hostile language, public displays, withdrawn and unresponsive, scratches, hits, steals)

5. Persons with Minimal Adaptive Skills

- Able to perform few activities of daily living* and then only with considerable assistance, but have no overriding physical, medical, or behavioral problems limiting their potential to do more for themselves.
- scores on tests of intelligence ranging below 35
- severe auditory, visual, or cognitive impariment, does not interact or relate to environment.
- does not feed self
- must be dressed/undressed completely
- does not tend to personal hygiene

6. Persons with Moderate Adaptive Skills

- able to do most activities of daily living* with supervision and assistance and who have no overriding phsyical, medical, or behavioral problems limiting their potential to do more for themselves.
- scores on tests of intelligence ranging from about 35 to 49

7. Persons with High Adaptive Skills

- able to perform most activities of daily living with intermittent supervision
- scores on tests of intelligence ranging from 50 to 70

---

* Activities of daily living include: eating, toileting, personal hygiene, dressing, money handling. shopping, reading and writing, care of personal belongings, interaction with others, participation in group activities, house cleaning, use of tools, sense of responsibility, and various vocational activities.

APPENDIX D

DESCRIPTION OF CLIENT SERVICES

INTRODUCTION

Save their particular handicaps, individuals with developmental disabilities are no different than anyone else. All require food, clothing and shelter. In the event they become ill, they require the services of health practitioners. To the extent that their impairment limits their ability to care for themselves (self-care skills), move about (mobility skills), and carry on activities of daily living, educational and vocational pursuits, they require supervision and support. At the same time, in the interest and to the benefit of both the individual and society, they must be afforded the opportunity to learn those skills necessary to increase their independence and reduce their dependence on others.

Stated in terms of particular service requirements, this translates into six general classifications of services, each of which contains some number of service subclassifications or types (See Figure 1). These services may operate in either centralized or noncentralized settings. This paper describes the service classifications, service sub-classifications, and service environments.*

Classifications of Services**

(1) Case Coordination Services

Case coordination services include those individualized needs assessment, planning, service coordination, and follow-up services necessary to make the delivery system work well for clients.

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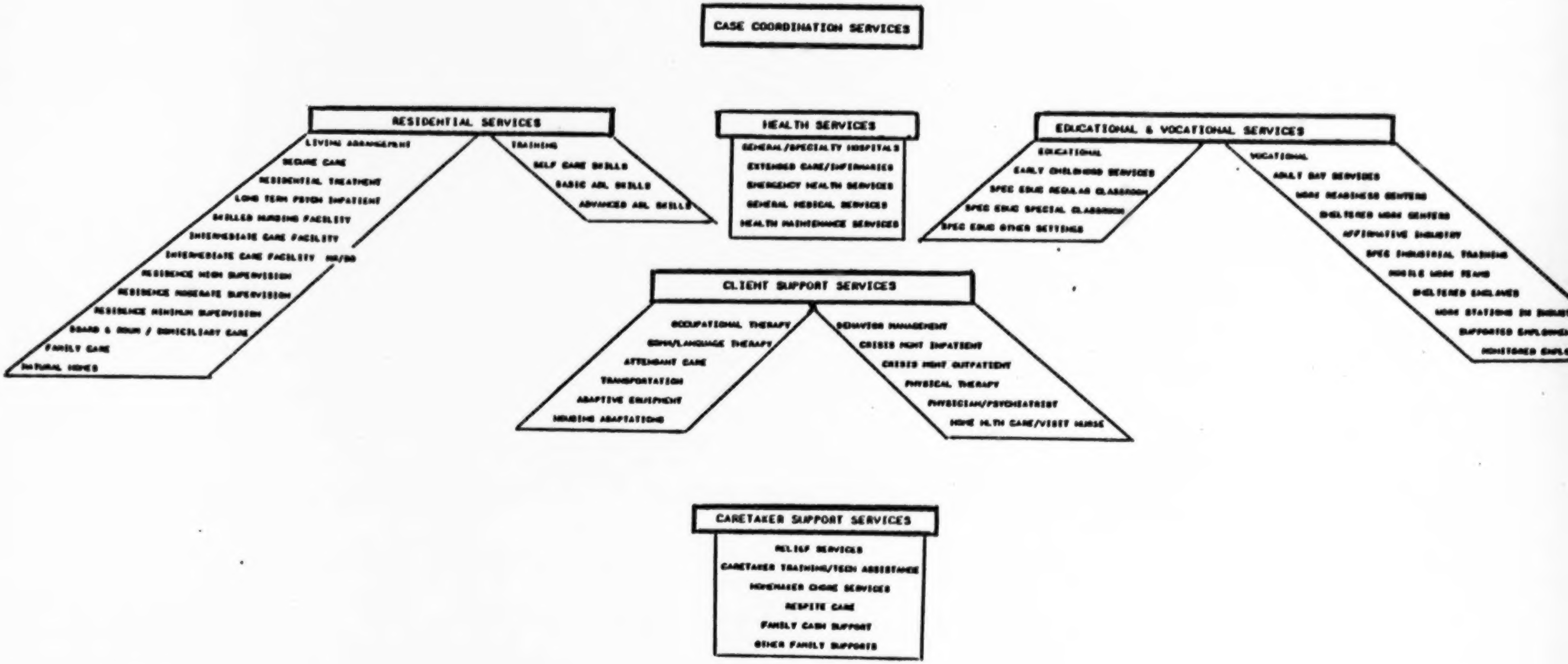
* Note: Planners are not constrained to choose services from the model's service menu. However, to the extent that this menu contains no counterparts to the particular services conceived by planners, planners will have to set their transition probabilities, and arrive at their own estimates of service costs. Preventive services will be added at a later date.

** Note: The six service groups described below represent direct or indirect services to persons with developmental disabilities. In the future the Model will include preventive services aimed at reducing the incidence of developmental disabilities.

SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES



(2) Residential Services

Residential services include at a minimum the provision of food, clothing and shelter, the basic level of supervision necessary to insure the safety and well-being of clients, and the provision of some training in self-care and community living skills.

(3) Health Services

Health services include services for evaluating the health status of individuals, for identifying and alleviating those acute conditions and for managing those chronic disabling conditions to the point where clients can function at the levels at which they would be able to function were it not for those conditions.

(4) Educational and Vocational Services

Educational and vocational services include services designed to enhance the physical, communication, social; affective and cognitive development of persons in order that they achieve and sustain the behaviors and skills necessary for them to maintain a lifestyle as culturally normative and free of outside support as possible.

(5) Client Support Services

Special client support services include services designed to ameliorate client chronic and disabling physical and behavioral conditions to the point where clients can function at or near the levels at which they would be able to function were it not for those conditions.

(6) Caretaker Support Services

Caretaker support services include the provision of those services that are necessary for the residential, habilitative and health programs to work efficiently and effectively.

Service Environment

Services may be centrally located as part of a residential center, campus, school, cluster..., or may be located at sites scattered throughout a community and administered by a single agency or by a number of independent agencies.

Centralized programs, commonly termed "institutions," are presently defined as those serving 64 or more residents. As with most large organizations, centralized programs characteristically:

- Employ staff more specialized in function (e.g., physical therapists, psychologists, residential aides, residential supervisors, laundry workers, housekeeping staff, plant maintenance staff); and
- Provide more programs, goods and services, in-house (e.g., recreational programs, religious services, library services, fire and police protection) than do smaller, more decentralized programs.

They are populated exclusively by persons with developmental disabilities and their caretakers and are communities separate and distinct from the larger communities within which they are located. As such, they inherently violate the generally accepted principles of normalization and community integration. Accordingly, though the model does not preclude it, large centralized facilities should not be the organizational scheme of choice, particularly in the case of programs serving clients who have no serious medical, physical, sensory, or behavioral conditions that prevent them from participating in the life of the larger community.

Service Descriptions

1.0 Case Coordination Services

All clients require case coordination services at some level to ensure that they receive those services they need to function adequately in the least restrictive setting possible. These services should be rendered preferably by individuals or organizations other than those providing client services. These services entail identifying eligible clients, assessing client needs, advocating on behalf of clients, planning to meet these needs, linking the client with various service providers, and linking service providers with one another to assure that services are well coordinated and provided in a timely manner.

2.0 Residential Services

There are twelve basic types of living arrangements and three levels of training pertaining to activities of daily living available to persons with developmental disabilities.

2.1 Living Arrangements

2.1.1 Secure Residential Care

A secure residential facility is any facility that employs, on a regular basis, locked doors or other physical means to prevent persons from leaving the facility. For our purposes, secure facilities include both correctional and mental health facilities where the program of the facility regularly includes confinement of residents to the physical spaces and/or grounds of the facility.

2.1.2 Residential Treatment Center for Children with Emotional Disturbances

A residential institution that primarily serves children who have moderate or serious emotional disturbances, and that provides treatment services, usually under the supervision of a psychiatrist.

2.1.3 Long-term Psychiatric Inpatient Facilities

A mental hospital providing long-term in-patient psychiatric treatment to adults under the supervision of a psychiatirst.

2.1.4 Skilled Nursing Facilities

Establishments with three or more in-patient beds that provide for persons who are not in an acute phase of illness but who require 24-hour supervision and observation: (1) Diagnosis and treatment services under the direction of a medical director or medical advisory who is a physician, and (2) continuous nursing care, planned, performed, supervised and/or directed by a registered nurse who is available on an around-the-clock basis.

2.1.5 Intermediate Care Facility for the Mentally Retarded (ICF/MR)

A facility providing 24-hour preventive and supportive nursing care and individualized programs of services to persons with developmental disabilities and with a stabilized health problem. Includes residents with physical handicaps who must be carried, wheeled or led from the building by others in emergency situations. The program is directed toward independent living skills and self-care. The facility must be certified as an ICF/MR under the provisions of 45 CRF 249.12.

2.1.6 Intermediate Care Facilities

Establishments with three or more in-patient beds that provide 24-hour care for persons who are not in an acute phase of illness but who require care that is supportive or preventive in nature. Limited nursing care, planned, performed, supervised and/or directed by a registered nurse on a daily, but necessarily round-the-clock basis.

2.1.7 Residences Providing High Supervision

Residential arrangements where 24 hour awake supervision is required to manage clients with behavior problems or to assist clients with activities of daily living. Persons living in this type residence require assistance, prompting, or physical force to leave the building in emergency situations.

2.1.8 Residences Providing Moderate Supervision

Residential arrangements where 24-hour (not awake) supervision is provided by staff (live-in or shift); residents are capable of performing self-help skills and basic activities of daily living with continual supervision. Residents require reminding, verbal instructions or gestures to depart from the residence within a reasonable period of time when warned of danger by a signal device.

2.1.9 Residences Providing Minimum Supervision

In semi-independent living programs, residents have their own living quarters (apartments, small homes) with staff nearby and on-call. These quarters may be in close proximity or in scattered sites around town. Staff may reside in the same building or building complex as clients or in their own homes away from clients. Residents take care of their own housekeeping needs, but generally require intermittent training or supervision in certain areas of domestic activity or community independence (e.g., meal preparation, use of public transportation, banking, etc.). Daytime activities are most likely to be vocational in nature and to be in group-supervised work centers, supervised work placements, or independent job placements.

Residents do not require any reminding, verbal instructions, gestures or physical assistance from staff or other residents to depart from the residence within a reasonable period of time when warned of danger by a signal device (e.g., a fire alarm).

2.1.10 Board and Room/ Domiciliary Facilities

Board and room facilities generally provide sleeping rooms, meals, some housekeeping and a watchful eye but not formal supervision or training. Most boarding homes are generic programs that are open to anyone who pays to stay. Some are specially licensed or contracted to provide care and supervision for one or more persons with developmental disabilities. Most states require board and supervision homes to be certified by the Department of Health and Welfare for safety. Boarding homes are usually operated by private home owners (proprietors) who rent rooms to one or more residents within their homes. Some boarding home proprietors charge extra for food and personal services (i.e., laundry, transportation, etc.).

2.1.11 Family Care Homes

The primary characteristic of a Family Care Home is that it utilizes an existing household for delivering services. Home care providers offer care in their own homes to 1-6 handicapped not family members. All states have "generic" foster care programs serving mostly children and sometimes children with handicaps. Many states also sponsor specialized foster or family care programs for adults with developmental disabilities as well as children. Surrogate "parents" are paid to provide lodging, meals, clothing, as well as instruction and habilitation in some instances. In addition, "parents" are reimbursed for medical, dental and other expenses necessary to provide a home for the resident.

A family home may serve as a temporary, short-term or long-term placement. While the goal of generic foster homes is to do whatever can be done to reunite foster children with their natural parents, specialized foster placements tend to long-term. Some homes provide only limited personal care (e.g., help with eating and dressing); these may be termed "personal care homes."

Family home care providers need no special education or credentials, but should receive training on ways to normalize relationships in the "family" and in the use of special instructional techniques. Personal home care providers may also require training in medical management, first aid, CPR, adaptive equipment and holding and transfer techniques. Family care provider programs may be administered directly by a government agency or indirectly through a non-profit agency under contract to the government.

2.1.12 Natural Homes

This category refers to those living at home with their natural, conjugal or adoptive families, or living independently without system support.

2.2 Training in Activities of Daily Living

Successful adaptation to community life requires that persons with developmental disabilities be capable of performing a variety of daily living skills. Moreover, because community life can be complex and unpredictable, these persons must be prepared to perform learned skills as needed under varying circumstances.

Though public school and adult day care services teach numerous community life skills, the content of such instruction does not span the full range of daily living skills, especially as the child grows older and his or her instruction focuses increasingly on vocation. In addition, present evidence shows that certain skills are learned and retained best by persons with developmental disabilities, if they are taught in the setting where a given skill will be most often required. For instance, fixing one's bed often is taught best in the learner's own room using his or her own bed. Similarly, crossing streets safely is taught best by systematically exposing the learner to numerous intersections and traffic conditions.

These considerations strongly suggest that instruction provided by public school or adult day services must be coordinated with and supplemented by those who provide guidance and supervision during other parts of the client's day. These persons could be paid professionals who staff the client's residence or family members who provide care in the family home.

Different types of community living skills must be learned depending on the characteristics of the learner (e.g., extent and type of disability, age), the learner's preferences and residential placement, the characteristics of the community surrounding the learner's residence, and the capacity of the learner's primary caretakers to teach.

2.2.1 Training in Self-Care Skills

This training covers the essential skills that are needed to progress from a highly supervised living arrangement to a moderately supervised arrangement. Generally, instruction is focused on the following areas:

- Self-help. This area pertains to basic skills related to self-care and can involve instruction regarding: toileting, eating/drinking, mobility (e.g., walking, crawling), basic communication, dressing/undressing.
- Personal hygiene. This area pertains to maintaining a neat and clean appearance and could involve instruction in: teeth and mouth care, skin care, bathing/showering, use of deodorant, hair care, shaving, clothing care/laundry, menstruation, care of personal prosthetics (e.g., hearing aids, eyeglasses.
- Personal Safety. This area pertains to maintaining one's personal safety. It may involve instruction in: leaving a given building in the event of fire, basic first aid, or simply gaining the attention of staff in the event of illness or injury.

2.2.2 Training in Basic Community Living Skills

This training covers skills needed for progress from a moderately supervised living arrangement to a minimally supervised living arrangement. Many persons whose instruction is focused on basic community living skills may also receive training pertaining to the above noted self-care domains. Such training might be designed to assure the maintenance or generalization of learned skills.

This level of instruction involves teaching basic or "entry level" skills in any of the following areas:

- Food preparation. This area pertains to those skills necessary for preparing foods and may include instruction in: stove/oven usage, following recipes, cooking specific meals.
- Household management. This area pertains to those skills necessary for managing and maintaining one's living area and may involve instruction in: fixing one's bed, household cleaning, refuse removal, washing and drying laundry, miscellaneous chores, and use of electrical appliances and telephone. .
- Leisure. This area pertains to those skills needed for taking full advantage of one's leisure time and may involve instruction in: domestic hobbies, playing table games, athletic endeavors, fine arts, camping.
- Shopping. This area pertains to choosing the appropriate store in which to shop for specific item(s) and to the variety of skills needed to find and purchase needed item(s). Such instruction may revolve around: grocery shopping, shopping in department stores, shopping in specialty shops.

3. Health Services

There are five general types of health services available.

3.1. General/Specialty Hospitals

Establishments with organized medical staffs provided permanent facilities that include at least six in-patient beds and whose primary function is to provide diagnosis and treatment services, including continuous nursing care, for patients who have a variety of medical conditions, both surgical and non-surgical. These hospitals may be used on a short or long-term convalescent basis or for acute medical problems.

3.2. Extended Care or Infirmary Facilities

Establishments with three or more short-term in-patient beds that provide for persons who are not in an acute phase of illness but who require 24-hour supervision and observation: (1) Diagnosis and treatment services under the direction of a medical director or medical advisor who is a physician, and (2) continuous nursing care, planned, performed, supervised and/or directed by a registered nurse who is available on an around-the-clock basis.

3.3 Emergency Health Services

Diagnosis and treatment in response to the perceived need of an individual for immediate health care to prevent loss of life or aggrevation of physiological and psychological illness or injury. The three key components of an emergency health services program are: (1) Emergency communication (including hotlines); (2) Emergency transportation; and (3) Emergency treatment (psychiatric and medical).

3.4 General Medical/Laboratory Services

These services include the diagnosis and treatment of non-emergent physical diseases and other ill-health conditions or their symptoms by techniques and interventions characteristic of general practitioners and distinct from those used in surgical or other major medical interventions requiring hospitalization.

3.5 Routine Health Maintenance Services

Routine health maintenance services include individual education, routine examination, and the use of drugs, substances or devices to protect an individual against disease, promote his or her optimum health, and assist in assuring the well-being of potential offspring. Illustrative service categories include: immunization, well-person maintenance, dental prophylaxis, and evaluation and screening of individuals known to be at risk relative to specific diseases or conditions.

4.0 Educational and Vocational Services

In most states children with disabilities become eligible for special education services as soon as their disability is confirmed through evaluation, and remain eligible until they reach 22 years of age. Following their public school education, most persons with developmental disabilities require additional instruction related to community life and vocation. This section presents the range of public school and post-school day services available to these persons.

4.1 Educational Services. Public school services for persons with developmental disabilities are congruent with the principle of "mainstreaming." This concept holds that individuals should receive services concomitant with their habilitative needs within the least restrictive setting possible. Specifically, special education means "the provision of services additional to, supplementary to, or different from those provided in the regular school program. Instructional techniques, materials and equipment are specifically designed to meet the needs of persons with disabilities."

Programs available through the public schools can be sorted into two age-related categories: early childhood services and special education services. Special education services may be provided in three types of settings.

4.1.1 Early Childhood Services (ages 0 through 5 years).

These services are designed to maximize the child's attainment of age-appropriate skills in a variety of areas including motor development, communication, socialization, self-help and cognition, and to diminish the need for specialized services later in life.

This type of infant stimulation or pre-school instruction can be undertaken either in the child's home, in an alternative setting like a public school or day care center, or in some combination. These services may be delivered in settings serving only persons with developmental deficits or in others that serve children without disabilities as well.

4.1.2 Special Education Services.

Primary school services teach age-appropriate skills emphasizing different types of skills depending on the nature and extent of a child's disability. As the child with developmental disabilities grows older, instruction focuses increasingly on developing community life and vocational skills. Services received, however, will vary according to the type and extent of a child's disability. Services can be provided in any of three settings: regular classrooms, special classrooms, and other environments.

4.1.2.1 Regular Classrooms where children, most without handicaps, are instructed. Children who are taught in this setting may also receive instruction from itinerant or school-based tutors or may attend instructional sessions in resource rooms.

4.1.2.2 Separate Classrooms where all children in the class have a disabling condition. These classes may cater to specific disability types or levels, or may serve children with varying capabilities or disabling conditions. Children who are taught in this setting may also receive some instruction in a regular classroom and/or share time with children in a regular school during activities such as sporting events, dining, and assemblies.

4.1.2.3 Other Environments where students receive specialized instruction. These environments can include hospitals, sanatoria, convalescent homes, or community residences. About 1% of students requiring special education services are served in these segregated environments.

4.2 Vocational Programs. These programs generally become available after the adult with developmental disabilities has left the public school system. Ten types of programs are described.

4.2.1. Adult day services (ADPS)

ADPS are defined and funded variously in different states (e.g., activity centers, pre-vocational programs, adult developmental centers, etc.). ADPS generally provide nonvocational services and are administered in each state by either social service or developmental disabilities agencies. ADPS generally provide social, self-care, communication, and work orientation training with the expectation that the individual will eventually move into either a Work Readiness Center or a Regular Program Workshop.

4.2.2. Work Readiness Centers

These centers are segregated facilities, serving only persons with disabilities, and offer training primarily in basic daily living skills (e.g., self help skills) or for treating severe maladaptive behavior. The purpose of such instruction is to provide individuals with fundamental skills, in anticipation of subsequent vocationally oriented training. Assignment to these types of centers is considered temporary; as individuals acquire fundamental skills they should advance to less restrictive vocational alternatives.

A Work Activity Center (WAC) is one type of Work Readiness Center. WACs are defined as a physically separate department of a workshop that provides therapeutic activities for handicapped workers whose physical or mental impairments are so severe as to make their productive capacity inconsequential. Persons enrolled in work activity centers produce at a rate which is less than 50% of the production standards of a non-handicapped employee based on criteria established by the Federal Wage and Hour Division of the U.S. Department of Labor.

4.2.3. Sheltered Workshops

These workshops, serving persons with disabilities exclusively, utilize work experience and related services to promote progress toward a productive vocational status. Clients receiving services in Regular

Program Workshops (RPWs) are covered by Department of Labor regulations which insure that they earn no less than 50% of minimum wage when they are working.

4.2.4. Specialized industrial training (aka, the Benchwork Model)

This type training usually takes place in a small, single-purpose, industrially-oriented workshop. This option is chacterized by being small, usually with less than twenty workers. Typically, programs are based in the community and provided employment through performance of complex assembly and production contracts. Non-handicapped workers can be employed in the same program.

4.2.5. Sheltered enclaves

These enclaves include small groups of disabled workers (usually four to eight) who are employed and supervised among non-handicapped workers in a normal business or industry. Continuous supervision is provided on-site by a trained human service professional. Workers may be employed directly through the business or industry, or remain employees of the non-profit organization which provides support to the individuals. Workers with handicaps work alongside others doing the same work, although in some situations handicapped workers may be grouped together to facilitate training and supervision.

4.2.6. Affirmative Industry

A principal reason for the development of these for-profit or non-profit enterprises is to create employment opportunities for persons with disabilities within settings that are highly integrated with nondisabled workers. Often, such programs are an outgrowth of a non-profit vocational endeavor (e.g., sheltered workshop). Except for the proportionately greater number of disabled to nondisabled workers, these program environments resemble sheltered enclaves (See 4.2.5). Continuous supervision is provided on-site by a trained human service professional. Workers may be employed directly through the affirmative industry or may remain employees of a parent non-profit human service organization.

4.2.7. Mobile work force teams

These teams or work crews are comprised of approximately five individuals who spend their day away from the rehabilitation facility performing service jobs in community settings. The agency sponsoring the work crew contracts with an outside organization or business to perform maintenance, groundskeeping, janitorial services or similar tasks. Workers are paid by the rehabilitation agenecy. A training supervisor from the agency accompanies each work crew.

4.2.8. Work stations in industry

These stations provide group training of the client/trainee at the industry site. Training is conducted by a habilitation representative or by company personnel. As training progresses, any of three outcomes may occur: 1) as an individual demonstrates competence, training is phased out and the client becomes a regular employee of the host industry; 2) clients may obtain similar jobs as regular employees in another setting; or 3) clients may remain in a training phase at the industry site or at some alternative site.

4.2.9. Supported work

Supported work is an approach that provides intense, ongoing support services to severely handicapped clients placed into competitive jobs. This model utilizes a job trainer or job coach who provides: job placement services to match the client with an appropriate job in business or industry; one-to-one job-site training and assistance until the client can perform the job to competitive standards; and ongoing follow-up services for as long as necessary to enable the client to maintain the job.

4.2.10. Monitored employment

Monitored employment refers to the time-limited job placement and follow-up services required to enable a handicapped wokrer to obtain and maintain employment, including: job placement assistance; support in adjusting to the workplace; and job monitoring and follow-up. A representative of the habilitation agency maintains communication with the employer, periodically monitors client performance and work adjustment, and helps resolve any job-related difficulties that emerge. These services are eventually faded out, and the model is not designed to provide ongoing support services for an indefinite period of time.

5.0 Client Support Services

Persons with chronic or overriding disabling conditions may need any of 11 specialized services in order to function at the level at which they would be able to function were the condition ameliorated. The 11 services are defined below:

5.1 Attendant Care Services

Provision of services by a paid employee of an attendant care agency or the person with disabilities who provides regular in-home physical assistance with essential activities of daily living (e.g., bathing, dressing, eating) to a severely disabled person who is unable to perform those activities alone. The services of an attendant may be shared by two or more persons with medical, physical or sensory handicaps.

5.2 Physical Therapy Services.

Include the therapeutic use of physical agents other than drugs (i.e., light, heat, water, electricity, massage, exercise, radiation) to maintain or increase the functioning of neuro-muscular, skeletal, cardiovascular, and respiratory systems.

5.3 Communication and Language Therapies.

Involve services to assess and enhance the individual's expressive and receptive language capabilities. These services may involve:

- Elimination or alleviation of speech defects
- Development or improvement of speaking intelligibility
- Learning alternative means of communication (e.g., sign language, language boards, bliss symbols)
- Elimination or alleviation of hearing defects
- Bio-feedback techniques

5.4 Occupational Therapy Services.

Involve services to motivate and/or encourage clients to learn skills necessary for their continued habilitation. Such services may include a variety of skill domains, including self-help, vocational or community living skills and can incorporate various modes of instruction including arts, crafts, and perceptual motor activities.

5.5 Behavior/Social Skills Programs.

Are used generally to replace maladaptive behaviors such as rocking, handbiting, fighting, or spitting with safer and/or more appropriate behavior. These services often include activities such as reinforcing alternate behaviors, discouraging or ignoring problem behaviors, correction/overcorrection, mild aversive stimulation (e.g., verbal reprimands, time out), or severe aversive stimulation (e.g., restraint, seclusion, punishment).

Additionally, these programs may involve any type of verbal therapy between a client and a qualified professional. Such therapy can take place in a protected environment, a professional office, or at the client's home and can involve problem-solving and guidance or intensive psychological therapy aimed at alleviating severe emotional and/or behavioral disorders. Counseling may be conducted with individual clients or groups of clients.

5.6 Crisis Management Programs: Outpatient Services.

Crisis management services are meant to respond to situational behavioral crises of persons with disabilities living in the community. These programs have the capacity to respond to crises on an outpatient or an inpatient basis.

Outpatient strategies may include:

- Temporary provision of specialized staff to go into the client's residence or day setting, daily if necessary, to provide the support and training necessary to resolve the crisis.
- Technical consultation from a crisis support team (e.g., psychologist, behavior specialist or psychiatrist) to provide caretakers with guidance for resolving the crisis.

5.7 Crisis Management Programs: Inpatient Services.

Crisis management services are meant to respond to situational behavioral crises of persons with disabilities living in the community. These programs have the capacity to respond to crises on an outpatient or an inpatient basis.

Inpatient crisis management services may include:

- -Temporary transfer of the misbehaving person to a an alternative care center (e.g., family placement home, respite home, alternative day program or specialized mental health facility).
- -Technical consultation from a crisis support team (e.g., psychologist, behavior specialist or psychiatrist)t o prepare caretakers coping with the problem behavior once the client returns to the original residential or day setting.

5.8 Adaptive Equipment Programs.

Involve the development or purchase of specialized equipment to enhance the client's qualify of life and/or promote his or her habilitation. Such equipment may include:

- -Eyeglasses
- -Hearing aids
- -Special clothing
- -Dental braces
- -Arm/leg braces
- -Crutches
- -Wheelchairs
- -Special shoes

5.9 Housing Adaptation Programs.

Involve modifications made to the environment to enhance the client's quality of life and/or promote his or her habilitation. Such modifications may include:

- -Home barrier removal
- -Installing ramps
- -Installing grab bars
- -Installing specialized alarm systems or phones

5.10 Home Health Aides/Visiting Nurses Programs

Nursing services performed by licensed or registered nurses for persons who are housebound and in need of intermittent, temporary, or long-term house health care. Such services might be made available to family care providers for persons in need of temporary or long-term nursing care.

5.11 Transportation Programs.

Services designed to transport clients to and from their residence and/or between various service delivery sites (e.g., day program, health center, recreation sites).

6.0 Caretaker Support Programs

Six types of programs are available for purposes of maintaining or improving the caregiving capacity of professional staff and family members. These six services are referenced below:

6.1 Respite Programs.

Respite care is a residential service provided for persons with developmental disabilities whose primary need is a short-term living arrangement (of no more than 30 days) for reasons of crisis assistance to the individual family, periodic family relief, family vacation. Respite services, provided outside a client's home in any of the above-described types of residential programs. Respite services may also be provided in the home wherby family members providing care in their home are relieved of their caretaking responsibilities for a few hours, overnight, or several days by family sitters who stay in the house with the client.

6.2 Homemaker/Chore Service Programs.

Homemaker services are in-home services provided to help developmentally disabled individuals remain with their families or in their own homes. Homemaker services include services which involve caring for the family in the home during periods of need or crisis, and teaching family members techniques of home management.

6.3 Relief Programs.

These services provide caretakers with temporary substitute personnel to allow caretakers time away from care provision. These substitute personnel can act as:

- Family sitter programs. Whereby family members providing care in their home are relieved of their caretaking responsibilites for a few hours, overnight, or several days by family sitters who stay in the home with the client.

- Relief staff programs. Whereby substitute staff temporarily augment or replace professional staff in day care or residential settings for a specified period of time. These services are used primarily to allow staff to attend training sessions or meetings and to compensate for staffing irregularities due to emergencies (e.g., snow days) or excessive staff turnover.

6.4 Caretaker Training and Technical Assistance Programs.

These services equip caretakers to provide and obtain competent care for persons with developmental disabilities. These services include:

- Family education/parent training programs. These services provide family members with useful information in a variety of areas including: developmental expectations, instructional methodology, behavior analysis, health maintenance, consumer education, legal rights, and specialized topics relevant to individual needs.

- Professional staff training programs. These services provide staff at residential or day care settings with information in numerous areas including the program purposes, agency-specific expectations and routines, normalization, instructional methodology, behavior analysis, health maintenance, and other specialized topics. Often, completion of such training is related to job advancement and/or salary increases.

- _Technical assistance programs_. These services involve use of specialized consultants to augment existing caretaker training capabilities or to solve specific service-related problems.

6.5 _Family Cash Assistance Programs_.

These services provide money to families to offset the costs of habilitative materials or services. In this type program, families either receive a periodic subsidy or stipend to pay for future expenses or are reimbursed for certain costs incurred.

6.6 _Other Family Supports_

No two families or two persons with developmental disabilities are alike. As a result, family needs can vary significantly, suggesting that means should be established for providing families with multiple service options. Rather than listing all those services that may be offered families, this category is meant to include any other family support deemed appropriate, but not noted previously.

APPENDIX E

INFORMATION ON THE INVENTORY FOR CLIENT AND AGENCY PLANNING (ICAP)

INVENTORY FOR CLIENT AND AGENCY PLANNING

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The *Inventory for Client and Agency Planning (ICAP)* is designed as a general tool for managing client information in a number of areas important to planning and evaluating services for handicapped, disabled, and elderly people. It includes important identifying information; a description of diagnostic and health status; normative scores for adaptive behavior and problem behaviors; information on service level, service history, current placements and projected service needs; and data on support services and social-leisure activities. The *ICAP* is primarily a program and client management device rather than a detailed scale for planning individualized training programs. It may, however, assist in making initial decisions regarding service needs and in periodically evaluating an individual's behavioral changes and participation in various service options.

The *ICAP* provides a means of recording information on client status, development, and needs in a number of areas that are important to a wide range of community service agencies. The most extensive benefits will occur in both community and institutionally based residential programs, nursing homes and related services, educational programs, various daytime habilitation and work training programs for handicapped and disabled individuals. It is intended to provide managers with a screening instrument for initial case planning and as a device for generating descriptions of the aggregate characteristics and service needs of their populations, and allows for efficient collection and analysis of large amounts of information with potential for automated data system reports. The *ICAP* is, therefore, ideally suited for screening purposes, initial assessments of service, eligibility, program monitoring, program evaluation, and for use as a management information system to assist in public reporting and decision making.

I. IDENTIFYING INFORMATION

The *ICAP* gathers information required by many state and federal licensing regulations as well as criteria set forth in the federal government *Long Term Care Minimum Data Set* and other reporting requirements.

II. DIAGNOSTIC AND FUNCTIONAL LIMITATIONS

Provides detailed information on diagnostic status, medical, and physical characteristics, and important functional limitations in vision, hearing, mobility, and health. This information is essential for determining eligibility for support services, for screening for admission to residential or habilitation programs, and for evaluating program appropriateness on a continuing basis.

III. ADAPTIVE BEHAVIOR

Contains 77 carefully developed adaptive behavior items organized into four domains of independence: *Motor Skills, Social and Communitation Skills, Personal Living Skills*, and *Community Living Skills.* The adaptive behavior section provides a variety of normative scores by domain and a total independence score (age scores, percentile ranks, standard scores).

IV. PROBLEM BEHAVIORS

Consists of eight areas of problem behavior organized to provide a profile of maladaptive behavior. The problem behaviors are assessed within comprehensive categories and yield information on all specific maladaptive behaviors exhibited by an individual, the frequency and severity of their occurrence, and the behavior management procedures used consistently by people in the individual's environment. Special statistical scales are provided for interpreting clinically significant problem behaviors for each of the eight areas, and for four special indexes (internalized maladaptive index, asocial maladaptive index, externalized maladaptive index, and general [overall] maladaptive index).

V. ICAP SERVICE INDEX

The Service Index Score combines adaptive behavior and maladaptive behavior scores to yield an overall measure of a client's need for care, supervision, or training. The Service Index Score was developed in recognition of the fact that adaptive and maladaptive behaviors interact and that neither score alone is sufficient to predict service intensity required.

VI. SERVICES

Provides a brief description of an individuals service history including therapeutic and community-based support services, and a projection of future service needs.

VII. RECOMMENDATIONS

Provides space for listing general and specific recommendations for clients.

SPECIAL FEATURES

* The maladaptive behavior and problem behavior portions of the *ICAP* were normed on a national sample of nonhandicapped people from birth to mature adult.

* A structured scoring scheme is used throughout the *ICAP* which provides normative scores for adaptive behavior and problem behavior as well as level of services required.

* The *ICAP* is a self-administered booklet which is completed by an individual who knows the client well. It does not require a special interview.

* The design and format of the scale requires minimal sophistication in test administration. It does not require a professionally trained examiner.

* The entire instrument can be completed in 20 minutes or less.

* The client population for this scale are children or adults being considered

for in-home support services, residential care facilities and nursing homes, rehabilitation services, day programs, work programs, and educational programs.

- Automated data processing and computer scoring procedures are being developed to rapidly score large numbers of protocols and to produce highly useful management information profiles.

- Includes comprehensive information in many areas needed to assess eligibility, planning of services, and monitoring of client progress.

TECHNICAL RESEARCH

Extensive technical research was done on the *ICAP*. The adaptive behavior and problem behavior portions of the scale were standardized on a nationally representative sample of children and adults. Additional studies on over 2,000 handicapped children and adults in a variety of educational, residential, habilitative, and work settings provided additional information for the ICAP's development. The ICAP's *Technical Manual* (in press) summarizes the results of numerous reliability and validity studies. Median split-half reliability on Broad Independence for 1,510 non-handicapped subjects was .86; for more heterogeneous groups of handicapped subjects, median split-half reliabilities were above .90. Typical test-retest and inter-rater correlations were above .80 for adaptive and maladaptive scales. Validity data indicate that the ICAP differentiates educational, residential, vocational, and diagnostic groups well.

Currently, the authors of the *ICAP* are developing a data analysis program to provide efficient scoring and summary information for program administrators at the local, regional, and state levels.

Further information on the *ICAP* can be obtained by writing to:

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